

## Agenda – Petitions Committee

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Meeting Venue:

Committee Room 1 – Senedd

Meeting date: 23 January 2018

Meeting time: 09.15

For further information contact:

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Cynulliad  
Cenedlaethol  
Cymru

National  
Assembly for  
Wales

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- Paul Apreda, Petitioner
- Dr Sue Whitcombe, Chartered Psychologist

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# Agenda Item 2.1

## **P-05-794 Lowering the Voting Age to Sixteen**

This petition was submitted by Sgiliau, having collected 87 signatures online.

### **Text of Petition**

We call on the National Assembly for Wales to lower the voting age to sixteen for those elections where they have the powers to do so.

### **Additional information:**

We live in a democratic society in which all members should have the ability to be responsible for their choices in our country. At sixteen you can get married, have a baby, and pay tax. At sixteen you can contribute to the country's economy but are yet to be able to decide how this public money is spent.

### **Assembly Constituency and Region**

- Islwyn
- South Wales East

## Lowering the Voting Age to Sixteen

Y Pwyllgor Deisebau | 23 Ionawr 2018

Petitions Committee | 23 January 2018

### Research Briefing:

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**Petition number:** P-05-794

**Petition title:** Lowering the Voting Age to Sixteen

**Text of petition:**

We call on the National Assembly for Wales to lower the voting age to sixteen for those elections where they have the powers to do so.

### Background

The [Wales Act 2017](#) gives the National Assembly power to make provisions about Assembly and local government elections including the ability to lower the voting age. The relevant provisions are expected to come into force on 1 April 2018.

The minimum voting age for all elections and referenda in Wales, England and Northern Ireland is 18. In Scotland, 16 and 17 year olds were permitted to vote in the Independence Referendum in September 2014. According to the [Electoral Commission](#) in their report on the Scottish Independence Referendum, 109,593 16 and 17 year olds registered to vote in the Scottish referendum. 75% of the 16-17 year olds the Electoral Commission spoke to claimed to have voted and 97% of those who reported having voted said that they would vote again in future elections and referendums. The Scottish Parliament subsequently passed the [Scottish Elections \(Reduction of Voting Age\) Act 2015](#) reducing the voting age to 16 for the Scottish Parliamentary and local elections.

The Isle of Man, Jersey and Guernsey also have a minimum voting age of 16.

As outlined in the [House of Commons Library Research Briefing Paper on Voting Age](#), there were attempts during the passage of the European Union Referendum Bill 2015-16 to amend the Bill to allow the franchise for the referendum to include 16 and 17 year olds. The

amendment was agreed in the House of Lords by 293 votes to 211 but was subsequently overturned by the Commons.

Two Private Members' Bills have been introduced in the House of Commons with the objective of reducing the minimum voting age for UK elections. Both Jim McMahon MP's [Representation of the People \(Young People's Enfranchisement and Education\) Bill 2017-19](#) and Peter Kyle MP's [Representation of the People \(Young People's Enfranchisement\) Bill 2017-19](#) are scheduled for Second Reading on 11 May 2018. A [Private Members' Bill](#) to the same effect has also been introduced in the House of Lords.

In June 2017, in a briefing entitled [Votes at 16](#), the Electoral Reform Society stated their support for enfranchising 16 and 17 year olds for all elections and referenda. According to the Society:

Enfranchising younger people is one of the ways we can try to build a better democracy in the UK. There is a widening gulf between people and politics – we see lowering the franchise as vital to nurturing more active citizens for the future health of our democracy. Giving 16 and 17 year olds a vote provides an opportunity to get the next generation more engaged with politics.

## Welsh Government action

A Welsh Government [consultation on reforming local elections in Wales](#) closed on 10 October 2017 and responses are currently being analysed. As part of this, the Welsh Government consulted on extending the franchise to include all those aged 16 on polling day in Welsh local government elections. The consultation document notes:

It has been Welsh Government policy for several years to reduce the voting age to 16 and indeed the National Assembly by a clear majority voted in favour of this move in May 2013. Furthermore, the policy was included in the manifestos of the Labour Party, Plaid Cymru and the Liberal Democrats at the General Election. We should soon be in a position to implement this.

In a letter to the Chair of the Petitions Committee dated 5 December 2017, the First Minister stated that:

It is the intention of the Welsh Government that 16 and 17 year olds will be enabled to vote at the next elections to the National Assembly and local government.

## National Assembly for Wales action

From November 2014 – June 2015 [an Assembly consultation for young people](#) found that 53% of the 10,375 who took part were in favour of lowering the voting age to 16.

In February 2017 the Assembly Commission established an [Expert Panel on Electoral Reform](#). One of the purposes of the Expert Panel was to advise the Assembly Commission on the minimum voting age for Assembly elections. The Panel [reported](#) in December 2017 and recommended that the minimum voting age for Assembly elections should be reduced to 16 with effect from the 2021 election (Recommendation 14). According to the Panel:

The evidence we have considered suggests a reduction in the minimum voting age to 16 would be a powerful way to raise political awareness and participation among young people. In addition, if the Welsh Government legislates to reduce the voting age for local government elections in Wales from 2022, it would be extremely anomalous, and create additional administrative and political issues, if the voting age for Assembly elections from 2021 were not also reduced. The evidence suggests that higher salience elections are more likely to result in higher turnout and voter participation; it is therefore desirable that if the franchise is to be extended in Wales, it should first take effect at the higher salience Assembly election. [Report para 15.39]

The Panel also concluded:

To ensure that young people are encouraged and supported to exercise their right to vote, any reduction in the minimum voting age should be accompanied by appropriate, effective and non-partisan political and citizenship education. [Report para 16.38]

On 10 January 2018, in a letter responding to this petition, the Llywydd stated that:

the Assembly Commission will consult in early 2018 on how the Panel's recommendations and the wider programme of reform should be taken forward.

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.



Eich cyf/Your ref: P-05-794  
Ein cyf/Our ref: FM -/05058/17

David John Rowlands AM  
National Assembly for Wales  
Cardiff Bay  
Cardiff Bay  
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5 December 2017

Dear David

I am writing in response to your letter of 21 November, sent in your capacity as Chair of the Petitions Committee.

It is Welsh Government policy that the franchise for voting at local government and Assembly elections should be extended to include all those aged 16 or over on polling day. This was included in the consultation paper "Electoral Reform in Local Government in Wales", published in July 2017. Consultation ended last month and responses are currently being analysed.

16 and 17 year olds are already able to vote in Scottish elections and also voted in large numbers in the Scottish referendum of 2014. Young people have a high degree of interest in political matters and the Active Citizenship element of Personal and Social Education enables consideration of current events while they are still at school.

It is the intention of the Welsh Government that 16 and 17 year olds will be enabled to vote at the next elections to the National Assembly and local government.

Yours sincerely

**CARWYN JONES**

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.





**Elin Jones AC, Llywydd**

Cynulliad Cenedlaethol Cymru

**Elin Jones AM, Presiding Officer**

National Assembly for Wales

David Rowlands AM  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
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10 January 2018

Dear David

**Petition P-05-794 Lowering the Voting Age to Sixteen**

Thank you for your letter of 21 November 2017 in relation to petition P-05-794, which calls for the minimum voting age for elections within the competence of the National Assembly for Wales to be lowered to 16.

The Fourth Assembly Presiding Officer, Dame Rosemary Butler, led a consultation in 2015 on whether 16- and 17-year-olds should be entitled to vote. Over 10,000 young people from across Wales took part in the consultation, of whom 53 per cent said that the voting age should be lowered, 29 per cent said it should not, and 18 per cent were unsure.

As you will be aware, in February 2017 I appointed an Expert Panel on Assembly Electoral Reform, tasked with considering what the minimum voting age should be for Assembly elections, as well as matters relating to the Assembly's size and electoral system.

In December 2017, the Expert Panel published its report: [\*A Parliament that Works for Wales\*](#). It concluded that a reduction in the minimum voting age to 16 would be a powerful way to raise political awareness and participation among young people. The Panel noted that the Welsh Government intended to legislate to

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reduce the minimum voting age for local elections in Wales to 16 with effect from 2022, and suggested that:

*“...it would be extremely anomalous, and create additional administrative and political issues, if the voting age for Assembly elections from 2021 were not also reduced. The evidence suggests that higher salience elections are more likely to result in higher turnout and voter participation; it is therefore desirable that if the franchise is to be extended in Wales, it should first take effect at the higher salience Assembly election.”*

Issues relating to the minimum voting age are set out in chapter 15 of the Panel’s report, which makes three recommendations (included in the annex to this letter for ease of reference).

The Expert Panel’s report is part of the Assembly Commission’s wider Assembly reform work. As you will be aware, I announced last year that, following the unanimous agreement of the Assembly and a period of public consultation, the Assembly Commission had decided to introduce legislation to change the name of the institution to Welsh Parliament/Senedd Cymru.

In isolation, this change aims to achieve a better understanding among the public of the work of the Assembly, as well as encouraging greater engagement between the institution and the people and communities it serves. However, by encompassing wider reforms, any Assembly Reform legislation could also be an opportunity to:

- ensure that the institution truly has the capacity that it needs to serve the people and communities it represents;
- invigorate our democracy, and enthuse and engage young people;
- ensure that the Assembly’s other electoral and internal arrangements, while robust, also provide the flexibility which is appropriate for a mature legislature.

It was on the basis of exploring these wider opportunities that I announced in June that the scope of the Assembly reform legislation would be considered once



**Elin Jones AC, Llywydd**

Cynulliad Cenedlaethol Cymru

**Elin Jones AM, Presiding Officer**

National Assembly for Wales

the Expert Panel on Assembly Electoral Reform had reported and the degree of political consensus was clearer.

As I set out in my [Written Statement of 12 December 2017](#), fundamental constitutional issues of the nature considered by the Expert Panel cannot be separated from the political realities of representative democracy in Wales. Delivering change will require the building of political consensus within the Assembly and outside. The next phase of the Assembly reform work will therefore include wide engagement with all Assembly Members, with civic and political society, and, above all, with the people of Wales. To this end, the Assembly Commission will consult in early 2018 on how the Panel's recommendations and the wider programme of reform should be taken forward.

Yours sincerely

Elin Jones

Llywydd

Croesewir gohebiaeth yn Gymraeg neu Saesneg.

We welcome correspondence in Welsh or English.



## Annex: Recommendations of the Expert Panel on Assembly Electoral Reform relating to the minimum voting age

**Recommendation 14.** The minimum voting age for Assembly elections should be reduced to 16 with effect from the 2021 election.

**Recommendation 15.** If the Assembly does legislate to lower the minimum voting age for Assembly elections to 16, the Assembly Commission should work with the Welsh Government, the Electoral Commission, political parties and others to support and encourage young people to exercise their right to vote, most importantly through appropriate political and citizenship education and public awareness-raising, but also by such other means as may be appropriate.

**Recommendation 16.** The citizenship education put in place to accompany any reduction in the minimum voting age must:

- i Recognise the diversity of settings within which 16- and 17-year-olds may receive education and training, to ensure that those outside traditional school settings are also supported and encouraged to exercise their vote;
- ii Go beyond simply outlining democratic structures and formal processes, to engage and inform young people about the issues which matter to them;
- iii Ensure that young people have opportunities to learn about a full range of political opinions in a non-partisan way;
- iv Be delivered by teachers and educators who have themselves received high quality training in order to ensure that citizenship education is taken seriously, and to avoid both political bias and the perception of political bias;
- v Be subject to review after a suitable period to ensure its design and delivery met its objectives.

# Agenda Item 2.2

## **P-05-795 Causing Nuisance or Disturbance on NHS Premises**

This petition was submitted by Claire Thomas having collected 74 signatures online.

### **Petition text**

S119 of the Criminal Justice and Immigration Act 2008 created powers to deal with persons who cause nuisance or disturbance on NHS premises. This was never enacted in Wales, and there are no provisions to deal with persons who create problems for the NHS in this manner.

There are numerous individuals who cause issues whilst on NHS premises, and the police receive many calls to deal with such behaviour, but there is no way of dealing with the issue effectively as there is no specific offence which the police can use to deter people who, without reasonable excuse, either cause a disturbance or nuisance, refuse to leave the premises when asked, or is not on the premises for the purpose of obtaining medical advice, treatment or care.

### **Additional information**

The cost to health services and the police in dealing with persons who cause nuisance on NHS premises is significant. A number of these individuals present repeatedly, and there are no powers to deal with this. Their presence also causes distress to others who do present to the NHS for genuine reasons. S119 of the Criminal Justice and Immigration Act 2008 has been used successfully by police and health in England to address the issue since the specific section came into force in 2009, yet there is no power to do so in Wales, and although Welsh government suggested that there would be the development of similar powers to address the issue in Wales, this has not been forthcoming.

### **Assembly Constituency and Region**

- Cardiff Central
- South Wales Central

## Briefing for the Petitions Committee

Petition number: [P-05-795](#)

Petition title: **Causing Nuisance or Disturbance on NHS Premises**

Text of petition: S119 of the Criminal Justice and Immigration Act 2008 created powers to deal with persons who cause nuisance or disturbance on NHS premises. This was never enacted in Wales, and there are no provisions to deal with persons who create problems for the NHS in this manner.

There are numerous individuals who cause issues whilst on NHS premises, and the police receive many calls to deal with such behaviour, but there is no way of dealing with the issue effectively as there is no specific offence which the police can use to deter people who, without reasonable excuse, either cause a disturbance or nuisance, refuse to leave the premises when asked, or is not on the premises for the purpose of obtaining medical advice, treatment or care.

### Background – Tackling nuisance and disturbance behaviour

The *Criminal Justice and Immigration Act 2008 (CJIA)* introduced new provisions to give the police and staff working in the NHS the power to remove and to prosecute individuals causing a nuisance or disturbance on NHS premises.

[Sections 119](#) and [120](#) of the Act contain provisions for NHS staff to deal with nuisance or disturbance behaviour. Section 119 created a new offence of causing a nuisance or disturbance on NHS premises. Section 120 provides a power for police officers or authorised NHS staff to remove a person suspected of committing this offence. The Act only applies to NHS hospitals in England.

### Overview of the offence and power of removal

Section 119 is an offence of causing a nuisance or disturbance on NHS premises. A person commits an offence if they satisfy **all** of the following:

a) the person causes, without reasonable excuse and while on NHS premises, a nuisance or disturbance to an NHS staff member who is working there or is otherwise there in connection with their work, and

- b) the person refuses, without reasonable excuse, to leave the NHS premises when asked to do so by a police constable or an NHS staff member, and
- c) the person is not on the NHS premises for the purpose of obtaining medical advice, treatment or care for himself or herself.

Section 120 gives police constables, authorised officers (and appropriate NHS staff members authorised by an authorised officer) the power to remove a person reasonably suspected of committing an offence under Section 119. A person may be removed using reasonable force if necessary. An authorised officer cannot remove a person (or authorise another person to do so) if they believe a person requires medical advice, treatment or care, or that removal would endanger their physical or mental health.

The key staff figures involved in implementing the provisions are **Authorised Officers** (AOs), whose role is to assess an incident and to authorise removal of persons suspected of committing the offence, and **Appropriate NHS Staff** (ASs), whose role is to remove an offender when authorised to do so.

NHS England published guidance in March 2012 on how to implement the CJIA provisions ['Guidance on provisions to deal with nuisance or disturbance behaviour on NHS premises in England'](#).

### **Welsh Government Response**

Section 119 of the CJIA created a new public order offence of causing "a nuisance or disturbance" to a member of NHS staff. It is non-imprisonable and carries a maximum fine of 1,000. This section came into force in England on 30 November 2009. The Welsh Government would need to issue a Commencement Order to enact section 119 to bring the part of the Act into force in Wales.

In his response to this Petition received on 11 December 2017, the Cabinet Secretary for Health and Social Services states that he is "currently considering if it is now appropriate to enact Section 119 in Wales by issuing a Commencement Order.

### **National Assembly for Wales debates**

The National Assembly's Audit Committee published its report ['Protecting NHS staff from violence and aggression'](#) in July 2009.

### **Additional Information**

Health Boards in Wales have a duty of care to staff to protect them from harm in the workplace. The NHS has a legal obligation to identify the risk of violence and aggression and develop appropriate prevention strategies.

Figures obtained by the Royal College of Nursing via a Freedom of Information Request show that there were 18,000 physical assaults against NHS hospital staff in a five year period from 2011 to 2016.

The [Assaults on Emergency Workers \(Offences\) Bill](#) is a Private Member's Bill introduced by Chris Bryant MP in the House of Commons on 19th July 2017. The next stage will be the Report stage in the House of Commons on 27th April 2018. The Bill creates a new offence of assault and battery committed against an emergency worker (with an increased maximum penalty of 12 months imprisonment), and also creates a statutory aggravating factor that will apply when other assaults and related offences are committed against emergency workers.

Further information can be found in the House of Commons Library [Briefing](#).



Vaughan Gething AC/AM  
Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau  
Cymdeithasol  
Cabinet Secretary for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref VG/05160/17

David John Rowlands AM  
Chair - Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
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11 December 2017

Dear David,

Thank you for your letter of 20 November regarding Petition P-05-795 Causing Nuisance or Disturbance on NHS Premises and seeking my views on the issues it raises before your first formal consideration of this petition.

I have looked into this matter and I am currently considering if it is now appropriate to enact section 119 in Wales by issuing a Commencement Order.

I will write to you again in the New Year on this matter.

Yours sincerely

**Vaughan Gething AC/AM**  
Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau Cymdeithasol  
Cabinet Secretary for Health and Social Services

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

**Pack Page 40**

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

# Agenda Item 2.3

## **P-05-796 Calling on the Welsh Government to Ban The Use of Wild Animals in Circuses in Wales**

This petition was submitted by Linda Evelyn Joyce Jones, having collected 1,517 signatures online and 1,737 on paper. An associated petition on another website also collected 3,144 signatures.

### **Text of Petition**

We call on the Welsh Assembly to ask the Welsh Government to ban the use of wild animals in circuses in Wales. Animal Welfare (except hunting and animal experimentation) is a devolved matter in Wales.

In December 2015 Rebecca Evans AM (then Deputy Minister for Farming and Food) said "The Welsh Government believes there is no place for the use of wild animals in circuses".

Under her instructions the WG commissioned a independent report which took evidence from over 600 experts in the field. This report was published in July 2016, and the conclusions it reached were clear.

The report stated "The scientific evidence indicates that captive wild animals in travelling circuses do not active their optimal welfare requirements set out under the Animal Welfare Act of 2006". The report also stated" Life for wild animals in travelling circuses and mobile zoos does not constitute either a "good life" or a "life worth living".

In December 2016 Lesley Griffiths AM (Cabinet Secretary for Environment and Rural Affairs) stated that the WG were working towards a licensing system , similar to the one currently operated by DEFRA in England. It should be noted that this system was put in place by the UK Government in 2011 as a temporary measure until a ban was put into place.

It can clearly be shown by the licensing documents available in the public dominion that this licensing system fails the animals. The two animal circuses currently licensed by DEFRA have repeatedly breached the conditions of their licenses, and had them suspended at one time or another.

In a poll carried out by RSPCA Cymru 74% of the Welsh public wanted this outdated practice banned. They also submitted a petition to The Petitions Committee of the Welsh Assembly in 2015.

## **Assembly Constituency and Region**

- Arfon
- North Wales

## P-05-796 Calling on the Welsh Government to Ban The Use of Wild Animals in Circuses in Wales

Y Pwyllgor Deisebau | 23 Ionawr 2018  
Petitions Committee | 23 January 2018

### Research Briefing:

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Petition number: [P-05-796](#)

Petition title: Calling on the Welsh Government to Ban The Use of Wild Animals in Circuses in Wales

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The report stated "The scientific evidence indicates that captive wild animals in travelling circuses do not active their optimal welfare requirements set out under the Animal Welfare Act of 2006". The report also stated "Life for wild animals in travelling circuses and mobile zoos does not constitute either a "good life" or a "life worth living".

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It can clearly be shown by the licensing documents available in the public dominion that this licensing system fails the animals. The two animal circuses currently licensed by DEFRA have repeatedly breached the conditions of their licences, and had them suspended at one time or another.

In a poll carried out by RSPCA Cymru 74% of the Welsh public wanted this outdated practice banned. They also submitted a petition to The Petitions Committee of the Welsh Assembly in 2015.

## Background

### Animal welfare in Wales

The Assembly has legislative competence in relation to “animal health and welfare” pursuant to paragraph 1 of Schedule 7 to the *Government of Wales Act 2006*. The *Wales Act 2017* will not change the Assembly’s competence in respect of animal welfare.

The [Animal Welfare Act 2006](#) is the principal piece of animal welfare legislation in Wales and contains the general laws relating to animal welfare. It also gives the Welsh Ministers a range of powers, for example:

- section 12 – making regulations to promote animal welfare;
- section 13 – licensing or registration of activities involving animals; and
- section 14 – making of codes of practice.

(section 16 covers the making or revising of codes of practice by the Assembly).

As [stated on the Welsh Government’s website](#), under the [Performing Animals \(Regulations\) Act 1925](#) those who exhibit, use or train a performing animal in Wales [must be registered with their local authority](#) (this does not apply to training or exhibiting animals for use by military, police, or for agriculture and sport). This legislation gives powers to the police and councils to enter and inspect premises where animals are being trained and exhibited to check that animals are kept in suitable conditions that meet health, welfare and safety standards. Non-registration carries a fine of up to £2,500 and if a complaint of cruelty is proven it can lead to individuals being banned from future exhibiting or training of performing animals.

### England

In England, the [Welfare of Wild Animals in Travelling Circuses \(England\) Regulations 2012](#) requires that all travelling circuses that use wild animals must be licensed. The licensing conditions set out requirements for:

- Provision of care plans;
- Controlling who may access the animals;
- Arranging for full veterinarian care; and
- Welfare requirements for display, training and performance, as well as environment and transportation.

The regulations were made under section 13 of the *Animal Welfare Act 2006*. [Guidance \(PDF 654KB\)](#) was introduced November 2012 that contains animal welfare standards to be

complied with by licence holders. Regulation 1(4) contains a 'sunset' clause that means the regulations will cease to have effect seven years after they come into force.

The UK Government has considered on several occasions banning the use of wild animals in circuses. On 16 April 2013, the Department for Environment, Food and Rural Affairs (Defra) published a draft bill aimed at banning the use of wild animals in travelling circuses in England from December 2015. In its scrutiny report the Environment, Food and Rural Affairs (EFRA) Select Committee [recommended](#) that the Government revise its approach to the bill, suggesting a proscribed list of wild animals in circuses rather than a complete ban. The UK Government's [response](#) rejected this. The Committee also commented that it would be desirable for such a ban to be UK-wide. The government responded:

As the Committee is aware, Defra Minister Lord de Mauley wrote to his three counterparts in the Devolved Administrations last November offering to extend the territorial scope of the Bill to their countries. The Government remains committed to working with the Devolved Administrations on reaching a coordinated position on this matter before a Bill is introduced. [...] The Minister for Natural Resources and Food in the Welsh Government, Alun Davies, has already written to Lord de Mauley confirming he would want his officials to work with Defra to produce a Bill that applies to England and Wales.

On 20 February 2017, a [private Members bill entitled \*Wild Animals in Circuses \(Prohibition\) Bill 2016-17\*](#) was introduced in the House of Commons. Covering only England, it was expected to have its second reading on 12 May 2017, however, following the UK General Election, the Bill fell. No such similar legislation is currently listed in the 2017-19 Bills before Parliament, or draft Bills for 2017-18.

## National Assembly for Wales action

The use of wild animals in circuses has received considerable public attention and was the focus of a previous petition in the Fourth Assembly ([P-04-653](#)). Submitted by RSCPA Cymru, it called for a ban on the use of wild animals in circuses. The then Deputy Minister for Farming and Food, Rebecca Evans AM, responded to the petition by announcing an independent review of the evidence on welfare of animals in travelling and non-travelling circuses. Following this, the Petitions Committee agreed to close the petition.

The matter is also frequently the topic of questions in the Assembly. On 16 October 2017, Sian Gwenllian AM, [asked the Welsh Government](#) if there are any current legal barriers that prohibit the use of wild animals in circuses in Wales, and if these barriers would disappear in April 2018 (the expected commencement date for many provisions of the Wales Act 2017). The Cabinet Secretary for Energy, Planning and Rural Affairs responded that there were no legal barriers. On 15 November 2017 a [written question](#) from Steffan Lewis AM asked for a

written statement on the introduction of a ban on animal circuses in Wales. The Cabinet Secretary responded:

There is concern the welfare needs of some animals kept by Mobile Animal Exhibits (MAEs), including hawking displays, reindeer at Christmas events and, of course, performing wild animals in circuses cannot be met in a travelling environment. MAEs are diverse and there is no standard licensing regime or requirement for routine inspection. We must decide whether or not a change of policy and/or the law is required to protect the welfare of animals in MAEs. A licensing or registration scheme could improve the welfare of animals in travelling environments and also legitimise businesses operating as MAEs in Wales.

I recently consulted on the introduction of a licensing or registration scheme for MAEs. The consultation also asked for views on banning the use of wild animals in circuses. Officials are now analysing responses to the consultation, the first on this subject, which will be used to inform the next steps and I will make a statement on this before 15th December.

Details of the outcome of the consultation will be published on the Welsh Government website in due course.

## Welsh Government action

### Independent review into animal welfare issues in circuses

As already stated, the Welsh Government, in response to RSPCA Cymru's previous petition, commissioned an independent review into animal welfare issues in circuses that [reported](#) in January 2016. In examining the welfare (physical and mental) of animals in travelling circuses, it found that:

The available scientific evidence indicated that captive wild animals in circuses and other travelling shows do not achieve their optimal welfare requirements, as set out under the Animal Welfare Act 2006, and the evidence would therefore support a ban on using wild animals in travelling circuses and mobile zoos on animal welfare grounds.

This report highlights a 2009 survey by the RSPCA (updated in 2016) that found ten Welsh local authorities had banned circuses on their land.

### Consultation on Mobile Animal Exhibits

A [Ministerial statement](#) on 15 December 2016 by the then Cabinet Secretary for Environment and Rural Affairs set out that she was keen to address the welfare of animals used by 'Mobile Animal Exhibits' (MAEs) including circuses. It highlighted that her officials were working on developing a licensing or registration scheme for MAEs, which would address inspection and enforcement. The Welsh Government [consulted](#) (17 July to 8 October 2017) on the feasibility of such a system for MAEs that display domestic and exotic animals in Wales. The consultation document highlighted the following situation in Wales:

A data capture survey was carried out with Local Authorities in Wales at the beginning of 2017 which revealed there to be at least 53 MAES based in Wales. [...]

MAEs are diverse and there is no standard licensing regime or requirements for routine inspection. Some MAES are registered under The Performing Animals (Regulation) Act 1925. This is a lifetime registration with no specific inspection requirements. As such, it is unlikely that the welfare standards of many of Wales' performing animals are regularly assessed.

The statement also advises that the Cabinet Secretary had:

...not dismissed the possibility of a future ban on the use of wild animals in circuses in Wales and [has] kept the window open on the possibility of still being included in any UK Government Bill brought forward on this issue. However, we cannot wait forever for that possibility to arise.

The consultation, therefore, also sought views on Wales banning the use of wild animals in circuses.

A written statement and a Summary of Responses were [published](#) by the Welsh Government on 14 December 2017. In light of "majority of respondents" agreeing that there should be a licensing or registration regime for MAEs (with most favouring licensing over registration), the written statement indicates that the Cabinet Secretary has tasked officials with the development of a licensing scheme for MAEs. This will be subject to a public consultation and a Regulatory Impact Assessment. On the matter of a ban, the Summary of Responses states:

The strong feeling amongst respondents regarding a ban on the use of wild animals in circuses in Wales must be acknowledged. Officials will continue to work with Defra and the Devolved Administrations to consider cross-border issues.

## Wales Animal Health and Welfare Framework

The Welsh Government's [Wales Animal Health and Welfare Framework 2017-18 Implementation Plan](#) sets out two key delivery milestones for MAEs. Firstly, to consult on the feasibility for introducing a licensing or registration scheme for MAEs, and for this consultation to seek views on the banning of the use of wild animals in circuses. Secondly, to present the findings of the public consultation and next steps to the then Cabinet Secretary for Environment and Rural Affairs.

The implementation plan states:

Under the Wales Act 2017, there is now scope to consider the option of banning the use of wild animals in circuses.

## Response to petition

A response to the petition was received from the Cabinet Secretary on 29 November 2017. This reiterates the position set out in the Welsh Government's MAEs consultation. She notes



that responses to the consultation are being used to inform the next steps for a licensing or registration scheme for MAEs. She also states:

At present there are no circuses based in Wales and I have not dismissed the possibility of working with the UK Government to bring in a joint ban on the use of wild animals in circuses. Officials attend regular meeting with Defra and the Devolved Administrations and are committed to moving this policy area forward.

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

Lesley Griffiths AC/AM  
Ysgrifennydd y Cabinet dros Ynni, Cynllunio a Materion Gwledig  
Cabinet Secretary for Energy, Planning and Rural Affairs



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref P-05-796  
Ein cyf/Our ref LG/05175/17

David John Rowlands AM

[government.committee.business@wales.gsi.gov.uk](mailto:government.committee.business@wales.gsi.gov.uk)

November 2017

Dear David

Thank you for your letter of 21 November regarding a petition from Linda Evelyn Joyce Jones on banning the use of wild animals in circuses in Wales.

The Welsh Government is committed to ensuring a high standard of welfare for all animals kept in Wales is maintained at all stages of their life. The way we treat animals is an important reflection of the values of our society. Animals should be protected from pain, injury, fear and distress.

I recognise there is concern the welfare needs of some animals kept by Mobile Animal Exhibits (MAEs), including circuses, cannot be met in a travelling environment. MAEs are diverse and there is no standard licensing regime or requirement for routine inspection. We must decide whether or not a change of policy and/or the law is required in Wales to protect the welfare of animals in MAEs. A licensing or registration scheme could improve the welfare of animals in travelling environments and also legitimise businesses operating as MAEs in Wales.

With this in mind, I have recently consulted on the introduction of a licensing or registration scheme for MAEs. I also asked for views on banning the use of wild animals in circuses. The public consultation, which lasted 12 weeks, closed for responses on 8 October 2017.

Officials are now analysing responses to the consultation, the first on this subject, which will be used to inform the next steps. Details of the outcome will be published on the Welsh Government website in due course.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

At present there are no circuses based in Wales and I have not dismissed the possibility of working with the UK Government to bring in a joint ban on the use of wild animals in circuses. Officials attend regular meetings with Defra and the Devolved Administrations and are committed to moving this policy area forward.

Regards  
Lesley

**Lesley Griffiths AC/AM**

Ysgrifennydd y Cabinet dros Ynni, Cynllunio a Materion Gwledig  
Cabinet Secretary for Energy, Planning and Rural Affairs

# Submission to the Petitions Committee of the Welsh Assembly.

## Petition title “calling on the Welsh Government to ban the use of wild animals in circuses in Wales”

Thank you for giving me this opportunity to provide this supporting statement .  
Lesley Griffiths' AM Cabinet Secretary for Energy Planning and Rural Affairs in response to my petition stated “ the way we treat animals is an important reflection of the values of our society. Animals should be protected from pain, injury, fear and distress “.

### The present position in Wales

Although no animal circuses are currently based in Wales, many do extensively tour our country. Attracted no doubt by the fact that we have a thriving tourist industry. Circus Mondao visit every year from April until July . Peter Jolly's Circus usually tour for two months or so dipping in and out of Wales, the last time they visited was 2016. Thomas Chipperfield toured Wales extensively in 2015 with his “educational show ” An Evening with Lions and Tigers (he and his big cats formally toured with Peter Jolly's Circus ). In total these circuses that feature wild animals are on the road for nine months of the year in England and Wales.

They use private land, as many if not all Councils in Wales will not allow them to use their land. The sites they use include land at garden centres, car boots sales, caravan and holiday parks, sea fronts and beaches. Together with land close to major roads like the A55 in north Wales, dual carriageways in Cardiff, Swansea, Hengoed and Neath. Land seems easier to find in the north which is more rural, and of course attracts more tourists. The circuses have teams of people who move into an area two weeks before their circus arrives. They put up their posters by illegally fly posting anywhere they can ( these remain long after they have left ) even in areas of outstanding natural beauty such as the Snowdonia National Park. Once their circus arrives in a town the signs on the highway go up, again illegally without the permission of the LA. They make their money, they leave so bring nothing to the economy of Wales . They also take no account of our culture, history or more importantly our Welsh language .

To keep wild animals they need a licence, which is granted by the LA where they are based. To tour they need a licence which is granted and policed by DEFRA. But at the present time this licence only extends to touring England. When I met with Councillor Dafydd Meurig and Ms Gwenan Mai Roberts, Public Protection Manager - Pollution Control and Licensing of

Gwynedd Council. They made it clear to me the challenges a visiting circus presents to their already stretched department. Ms Roberts also stated her colleagues felt they were operating with “one hand tied behind our backs “ . They can be refused entry to the private land to inspect the conditions the animals are kept in. Ms Roberts also admitted as far as the animals go “ we can only really check if their basic needs are provided for, and that they are moving around normally and their eyes, coats etc look okay “ . When Thomas Chipperfield visited Gwynedd in 2015 she stated that she was faced with “very challenging circumstances “ when she and a colleague inspected them.

If any concerns are identified then action can be taken, for instance to contact the RSPCA. But they often need police assistance to gain entry. By which time the circus has moved on, usually the longest period they remain in one spot in Wales is seven days. There has been only three successful prosecutions for animal cruelty in relation to animal circuses in England . Two of these related to the time the animals were in their winter quarters , so not on the road.

### **The recent consultation on Mobile Animal Exhibits.**

This was promised by the Welsh Government following on from the Harris report, which was published in July 2016. But the remit of the consultation was widened from just circuses that use wild animals. In the summary of responses to this consultation ( WG33753) it can be seen that the respondents felt the remit and title of this consultation were problematic. “ some thought that it was too broad and others were of the view that certain classes of animal, depending on their use should be excluded “.

In relation to wild animals in circuses only one question was asked, but the summary of responses stated “ there were 70 comprehensive responses to the consultation. A further 892 similar responses were received which only answered Questions 8 (on banning the use of wild animals in circuses ). This strengthens my belief that this consultation should have only been about wild animals in circuses, as originally promised by Rebecca Evans AM the former Minister for Environment, Farming and Rural Affairs.

The report also stated that “ the majority of respondents believe the use of wild animals in circuses should be banned and that wild animals cannot be cared for appropriately whilst in a travelling environment “.

### **The Harris Report.**

The remit of this report was “to provide the Welsh Government with an impartial literature review and an analysis of the scientific evidence available as to whether captive wild animals

in travelling circuses and other shows achieve their optimum welfare requirements set out under the Animal Welfare Act of 2006 and other relevant legislation “.

I think it is worth noting that this report took evidence from over 600 experts in the field, including those who work in the animal circus industry. The only differing of opinion occurred between those involved in the circus industry and the rest of the respondents in relation to the training techniques used by the profession and the impact the travelling life had on the animals used for example.

The conclusions of the Harris report stated that :

“ the scientific evidence indicates that captive wild animals in travelling circuses and mobile zoos do not achieve their optimum welfare requirements set out under the Animal Welfare Act 2006.”

“In our review of the needs of wild animals, we found that all of the “freedoms” are compromised in travelling circuses and mobile zoos “. that “ life for wild animals in travelling circuses and mobile zoos does not constitute either a " good life " or a " life worth living " .

I could also make mention of the numerous studies, reports etc that other government's and animal welfare bodies have commissioned through the years. Including Animal Defenders International, the Captive Animal Protection Society and the RSPCA ( England and Wales ).

All of the above-mentioned bodies submitted responses to both the Harris report and the recent consultation on MAE, as I myself did too.

### **The licensing system re wild animal circuses currently operating in England.**

In the light of Lesley Griffiths statement of 14/12/17 together with past discussions I have had with our First Minister Carwyn Jones AM. I think it's important members consider this subject.

On 13 May 2011 the UK Government announced its decision to introduce a licensing system rather than a ban on wild animals in circuses. In doing so the UK Government cited concern over a legal challenge to a ban in Austria. However, the case against the Austrian ban was later dropped.

The UK Government said that their licensing system would cover **all** aspects of life for a wild animal in a travelling circus environment including:

**Good accommodation and housing whilst being transported at a performance, and in winter quarters**

**Full veterinary care**

**Controlling carefully who has access to the animals**

**Diet including food storage, preparation and provision**

**Environment such as noise and temperature**

**Welfare during training and performance**

However the licensing documents in the public domain paint an altogether different picture.

These licence inspection reports concerning Circus Mondao are an example of the issues with reference to accommodation and housing.

<https://www.gov.uk/government/publications/reports-on-2-circuses-between-26-june-2014-and-22-january-2015>

At the time of the above inspection (at the animals winter quarters) the Inspector also raised concerns about the animals veterinary treatment.

It became clear to him during this unannounced inspection that Circus Mondao were self-medicating their animals, including their baby Camel (who was born on the road in Wales the previous year). The camel had "open and weeping sores on each of its legs". Circus Mondao's licence was instantly suspended, later to be reinstated, but only on certain conditions; one being that they wouldn't take their wild animals back to this location. They did exactly this in April 2017, with DEFRA having to insist certain animals were returned to their home base while they were at this location.

Veterinary treatment should be provided by a designated lead vet, who often lives close to the circuses home base. Veterinary consultations can of course be done by phone. Many

small animal veterinary practices right across Wales clearly excel in the range of treatments they can offer both companion and farm animals. But realistically how many would claim to see such animals as Reindeer, Camels, Zebra, Tigers and Lions on a regular basis? It's my understanding that the RCVS guidelines state that an animal should be registered with a veterinary practice before they are treated. Also ideally any vet who treats an animal should have the past clinical history, from previous vets to consult.

When Thomas Chipperfield was in Llanwnda near Caernarfon in 2015, it became clear that one of his Lions had sustained an injury to one of his rear legs. This prompted me to consider what veterinary provisions were available in our particularly rural area of north west Wales. In reality the RCVS University's Leahurst faculty located on The Wirral, 12 miles south of Liverpool would have been the nearest appropriate option with the expertise required to treat animals defined as wild.

I have read most of the travelling circus license applications, including the applications that were unsuccessful for example Thomas Chipperfield's and Anthony Beckwith before they toured Cymru in 2015. Also any related inspection reports from the DEFRA Inspectors, I can honestly say I have been haunted by their contents, especially with my background and love of animals.

### **Position in other countries.**

The practice of using wild animals in travelling circuses has been banned in over 35 countries. With the Republic of Ireland announcing their intention to ban at the end of this month. I believe Scotland's ban is effective from the 1<sup>st</sup> January 2018. Roseanna Cunningham Environment Secretary has been quoted as saying "this is an important act that will not only prevent travelling circuses ever showing wild animals in Scotland in the future. But will also demonstrate to the wider world that we are one of the growing number of countries that no longer condones the use of wild animals in this way".

Last week Michael Gove MP indicated that the UK Government intend finally to bring forward legislation that was first drafted five years ago. However in realistic terms, it will be next year before such legislation can be presented to the UK Parliament, if at all. I personally do not hold out much hope of this going forward in the UK Parliament.

### **In Conclusion**

The petition I present to you today contains 6,388 signatures, and as such will trigger a debate on the floor of The Senedd. These signatures were collected online and on paper from all over Wales. At events like food fairs, Dog Shows, Universities Freshers Fair's, The National Eisteddfod of Wales. People from all sections of our community willingly signed, many expressing the view that they thought this practice had already been banned. I have



been deeply humbled that many people have even thanked me for asking them to sign, and launching my petition in the first place. This is the second petition calling for a ban, to be presented to the Petitions Committee in three years. With RSPCA Cymru's petition of 2015 gaining over 7,000 signatures all from Wales.

It is clear the Harris report of 2016 gives the Welsh Government the independent scientific evidence to put a ban into place, as does the conclusions from the recent consultation on MAE.

It is my understanding that legislation can be brought forward by two routes. Either by primary legislation, or by way of the Animal Welfare Act of 2007. The Wales Act of 2011 gave the Welsh Government the power to act in these matters.

To me personally this isn't a political issue, it's an animal welfare issue. That is my background, as a former branch Trustee and Volunteer for an animal welfare organisation . For over forty years I have been fighting for a ban to be brought forward first by the UK Government and since 2011 the Welsh Government. Thomas Chipperfield touring Cymru in 2015, during which he visited my beloved home town of Caernarfon . Was truly abhorrent to me, and many others. My MP Hywel Williams said at the time " the days of loading animals onto the back of trucks, to tour our country purely for people's entertainment has long since passed " .

I urge you as a Committee and as Assembly Members to do everything in your power to ensure the Welsh Government acts in a timely manner to bring forward legislation to ban this outdated practice in Wales.

If I can assist members or the Welsh Government further in their deliberations I would be more than happy to do so.

**Linda Evelyn Joyce Jones 14/1/2018.**

# Agenda Item 2.4

## **P-05-797 Ensure access to the cystic fibrosis medicine, Orkambi, as a matter of urgency**

This petition was submitted by Rhian Barrance having collected 5,717 signatures online.

### **Text of Petition**

We call on the National Assembly for Wales to call for a resolution to ongoing negotiations between NHS Wales, the All Wales Medicines Strategy Group, the Welsh Health and Specialised Services Committee and Vertex Pharmaceuticals regarding access to the cystic fibrosis medicine, Orkambi, as a matter of the utmost urgency.

### **Additional Information**

418 people in Wales have cystic fibrosis (CF). CF is a life-shortening, inherited disorder. The median age at death for a person with CF in 2016 was just 31 years of age. CF is caused by mutations in the CFTR gene which result in the build-up of thick, sticky mucus in the lungs and other organs. Gradually, this build up causes chronic lung infections and progressive lung damage. The treatment burden for a person with CF is high and daily life can be a struggle.

Orkambi is a precision medicine that 40% of people in the UK with CF could benefit from. While conventional CF treatments target the symptoms, precision medicines tackle the underlying genetic mutations that cause the condition. Though Orkambi is not a cure, it has been found to slow decline in lung function – the most common cause of death for people with CF – by 42%.

In July 2016, the National Institute of Clinical Excellence (NICE) recognised Orkambi as an ‘important treatment.’ They were, however, unable to recommend the drug for use within the NHS on grounds of cost effectiveness and a lack of long-term data.

In June 2017, the Cystic Fibrosis Trust organised a day of national protest at the Senedd, Stormont, Holyrood, Downing Street and online to demand an end to the deadlock. Since the protests, the Welsh Health and Specialised

Services Committee (WHSSC) have presented the All Wales Medicines Strategy Group (AWMSG) with the portfolio approach developed by the drug's manufacturer, Vertex Pharmaceuticals.

We call on the National Assembly for Wales to call for a resolution to these ongoing negotiations between NHS Wales, the AWMSG, WHSSC and Vertex Pharmaceuticals as a matter of the utmost urgency. It is essential that a fair and sustainable method of reimbursement is found for Orkambi and for the exciting pipeline of future treatments.

People in Wales have been waiting too long for this transformative drug. They deserve better.

**Assembly Constituency and Region**

- Cardiff West
- South Wales Central

## Briefing for the Petitions Committee

Petition number: [P-05-0797](#)

Petition title: **Ensure access to the cystic fibrosis medicine, Orkambi as a matter of urgency**

We call on the National Assembly for Wales to call for a resolution to ongoing negotiations between NHS Wales, the All Wales Medicines Strategy Group, the Welsh Health and Specialised Services Committee and Vertex Pharmaceuticals regarding access to the cystic fibrosis medicine, Orkambi, as a matter of the utmost urgency.

418 people in Wales have cystic fibrosis (CF). CF is a life-shortening, inherited disorder. The median age at death for a person with CF in 2016 was just 31 years of age. CF is caused by mutations in the CFTR gene which result in the build-up of thick, sticky mucus in the lungs and other organs. Gradually, this build up causes chronic lung infections and progressive lung damage. The treatment burden for a person with CF is high and daily life can be a struggle.

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In July 2016, the National Institute of Clinical Excellence (NICE) recognised Orkambi as an ‘important treatment.’ They were, however, unable to recommend the drug for use within the NHS on grounds of cost effectiveness and a lack of long-term data.

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We call on the National Assembly for Wales to call for a resolution to these ongoing negotiations between NHS Wales, the AWMSG, WHSSC and Vertex Pharmaceuticals as a matter of the utmost urgency. It is essential that a fair and sustainable method of reimbursement is found for Orkambi and for the exciting pipeline of future treatments.

People in Wales have been waiting too long for this transformative drug. They deserve better.

## Policy background

Orkambi (lumacaftor-ivacaftor) is a medicine for the treatment of cystic fibrosis in patients aged 12 years and older who have a specific gene mutation (the F508del mutation). Cells contain two copies of the relevant gene, and Orkambi can be used in patients where both copies are affected by the F508del mutation. This equates to approximately 50% of people with cystic fibrosis, and according to the [Cystic Fibrosis Trust](#), Orkambi is effective in treating 40% of these cases in the UK.

Orkambi has been shown to slow the decline in lung function and significantly reduce infection and hospital stays. The Cystic Fibrosis Trust highlights [research](#) which demonstrates that Orkambi can slow down the decline in lung function experienced by people with cystic fibrosis by an average of 42%.

The 2014 [UK Cystic Fibrosis Registry](#) report states that there are 2,834 people in England, 243 people in Scotland, 118 people in Wales and 101 people in Northern Ireland who could stand to benefit from Orkambi, a total of 3,296 people.

Medicines undergo an appraisal process to determine whether the benefit to patients justifies the cost, before they can be routinely used to treat NHS patients. The National Institute for Health and Care Excellence (NICE) advises the NHS on both the clinical and cost effectiveness of some newly-licensed medicines. This advice has a statutory basis in England and Wales, with Welsh health boards legally obliged to fund NICE-approved medicines. The All Wales Medicines Strategy Group (AWMSG) has a remit to appraise new medicines that are not on the NICE work programme. Health boards in Wales also have a legal requirement to fund medicines approved by AWMSG.

As noted in the petition, [NICE guidance](#) (July 2016) does not recommend the use of Orkambi within the NHS in England/Wales on the grounds of cost-effectiveness and a lack of long-term data. Orkambi is also not recommended (by the Scottish Medicines Consortium) for use in NHS Scotland. Due to NICE's negative recommendation, Orkambi is not available for routine commissioning in NHS Wales.

The [NICE website](#) states that the key conclusions on this drug were:

Lumacaftor-ivacaftor is not recommended, within its marketing authorisation, for treating cystic fibrosis in people 12 years and older who are homozygous for the F508del mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) gene.

The committee concluded that longitudinal changes rather than acute changes in ppFEV1 were more clinically relevant for assessing long-term outcomes of cystic fibrosis. It also concluded that the reductions in pulmonary exacerbations seen with lumacaftor-ivacaftor treatment were clinically significant and important for managing cystic fibrosis.

The committee concluded that, even without including any of its preferred assumptions, the estimated incremental cost-effectiveness ratios (ICERs) were considerably higher than what is normally considered a cost-effective use of NHS resources.

The next NICE review on Orkambi is due in **July 2019**. Medicines in Wales can also be appraised by the All-Wales Medicines Strategy group (AWMSG). However the AWMSG would require information in addition to that received by NICE, following a negative decision by NICE.

The Cystic Fibrosis Trust has been publicising the petition with case studies on its [website](#), and is running campaign, *'Stopping the clock'*, on access to precision medicines like Orkambi. As described in the petition, the charity recently [protested outside the Senedd](#) about access to the drug.

## Response from the Welsh Government

The Cabinet Secretary for Health and Social Services states in his letter to the Committee that NICE issued final guidance in July 2016 and did not recommend Orkambi for routine use in the NHS in Wales or England. Furthermore **in December 2016, NICE re-issued its Technology Appraisal guidance under its "Do Not Do" guidance, emphasising that Orkambi should not be made routinely available.** The Cabinet Secretary highlights the significance of this:

Whereas NICE frequently issue guidance which does not advocate using a specific medicine for a certain condition, it is far rarer for NICE to explicitly advise that a medicine should not be routinely used at all. The NICE independent appraisal committee found that when compared to the current standard of care, **the clinical benefit offer** between NHS Wales, the AWMSG, WHSSC and Vertex Pharmaceuticals'; The Cabinet Secretary states that the AWMSG has contacted the pharmaceutical company, Vertex Pharmaceuticals, and 'has strongly encouraged them to make a submission to the AWMSG for appraisal'. He states:

Whilst Vertex has agreed in principle to submit clinical data for appraisal by AWMSG, they have not committed to any firm date for doing so. However, discussions have commenced with Vertex on the most effective approaches to appraisal for the additional license extensions due to come on stream over the next few years. My officials will ensure the future appraisal of lumacaftor/ivacaftor (Orkambi®) is covered.

In the interim, the Welsh Health Specialised Services Committee (WHSSC) has agreed a patient access scheme with Vertex Pharmaceuticals and it is available in the Welsh NHS, where clinically appropriate.

Whilst compassionate use agreements offer treatment at no cost for a fixed period, NHS organisations must consider the implications of entering into such agreements including the clinical benefits for patients and the longer term cost implication for the NHS.

Where medicines such as Orkambi are not routinely available within NHS Wales, a clinician may apply for the medicine on behalf of their patient to an Individual Patient Funding Request (IPFR) panel in the appropriate health board. The clinician would need to source sufficient evidence to demonstrate the clinical and cost effectiveness of the proposed intervention.

Vaughan Gething AC/AM  
Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau  
Cymdeithasol  
Cabinet Secretary for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Our ref VG/05162/17

David John Rowlands AM  
Chair - Petitions Committee.  
National Assembly for Wales  
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// December 2017

Dear David,

Thank you for your letter of 21 November regarding Petition P-05-797 from Rhian Barrance regarding access to the cystic fibrosis medicine, Orkambi®.

We believe everyone should have access to cost-effective, evidence-based NHS treatment and care at all times to meet their clinical needs. This means ensuring decisions about the availability of treatment are based on evidence of effectiveness and the extent to which the benefits are in proportion to the cost charged by the manufacturer. To achieve this, we are guided by the recommendations of the National Institute for Health and Care Excellence (NICE) and the All-Wales Medicines Strategy Group (AWMSG).

NICE issued final guidance in July 2016 and did not recommend Orkambi® for routine use in the NHS in Wales or England. In December NICE re-issued its Technology Appraisal guidance under its "Do Not Do" guidance, emphasising this treatment should not be made routinely available. Whereas NICE frequently issue guidance which does not advocate using a specific medicine for a certain condition, it is far rarer for NICE to explicitly advise that a medicine should not be routinely used at all. The NICE independent appraisal committee found that when compared to the current standard of care, the clinical benefit offered was modest and comes at a considerable cost. The Scottish Medicines Consortium has also turned down this medicine for the same reason.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

**Pack Page 63**

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

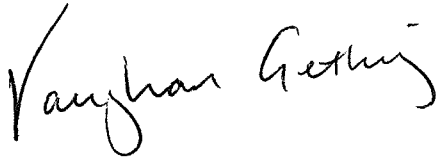
The All-Wales Medicines Strategy Group (AWMSG) has contacted the pharmaceutical company, Vertex Pharmaceuticals and has strongly encouraged them to make a submission to the AWMSG for appraisal. Whilst Vertex has agreed in principle to submit clinical data for appraisal by AWMSG, they have not committed to any firm date for doing so. If the manufacturer refuses to provide evidence about how well their medicine works, AWMSG cannot appraise it and cannot therefore issue a recommendation to make the medicine routinely available or not. However, discussions have commenced with Vertex on the most effective approaches to appraisal for the additional license extensions due to come on stream over the next few years. My officials will ensure the future appraisal of lumacaftor/ivacaftor (Orkambi®) is covered.

In the interim, the Welsh Health Specialised Services Committee (WHSSC) has agreed a patient access scheme with Vertex Pharmaceuticals and it is available in the Welsh NHS, where clinically appropriate.

Whilst compassionate use agreements offer treatment at no cost for a fixed period, NHS organisations must consider the implications of entering into such agreements including the clinical benefits for patients and the longer term cost implication for the NHS.

Where medicines such as Orkambi® are not routinely available within NHS Wales a clinician may apply for the medicine on behalf of their patient to an Individual Patient Funding Request (IPFR) panel in the appropriate health board. The clinician would need to source sufficient evidence to demonstrate the clinical and cost effectiveness of the proposed intervention.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive style with a large initial 'V'.

**Vaughan Gething AC/AM**

Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau Cymdeithasol  
Cabinet Secretary for Health and Social Services



# Cystic Fibrosis our focus

## **Petition consideration briefing:**

e-Petition: Ensure access to the cystic fibrosis medicine, Orkambi, as a matter of urgency

**We call on the Welsh government to agree a sustainable solution for cystic fibrosis medicines today and into the future.**

### **1. Cystic fibrosis**

Cystic fibrosis is a life-shortening genetic condition that affects over 10,400 people in the UK, including 398 people in Wales. Last year, half of all people who died with cystic fibrosis were under the age of 31.<sup>1</sup>

### **2. Precision medicine**

Traditional treatments for cystic fibrosis aim to lessen symptoms and complications. However, progressive damage still occurs, meaning that these symptoms and complications will inevitably increase with age.

New precision medicines target the dysfunctional protein that causes cystic fibrosis. They target specific mutations and have the potential to preserve or restore lung function, slow decline and improve life expectancy.

The first two precision medicines are Ivacaftor (effective for under 10% of people with cystic fibrosis) and Orkambi (effective for around half of people with cystic fibrosis in Wales).<sup>2</sup> Many further precision medicines are being developed. Within five years, around 90% of people with cystic fibrosis could be treated with new drugs<sup>3</sup> that transform cystic fibrosis from a condition that is life threatening to one you that you live with and manage.

People with cystic fibrosis in Wales have already faced significant delays in accessing new precision treatments and are increasingly concerned that they will not get to access these life-changing medicines.

### **3. Orkambi**

Orkambi is a precision medicine that tackles the underlying cause of cystic fibrosis rather than just managing the symptoms. The drug specifically targets the genotype with homozygous  $\Delta F508$  mutations which affects around 189 people in Wales.

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<sup>1</sup> UK CF Registry Report 2016, Cystic Fibrosis Trust, 2017.

<sup>2</sup> UK CF Registry Report 2016, Cystic Fibrosis Trust, 2017.

<sup>3</sup> <http://www.businesswire.com/news/home/20170718006344/en/>

# Cystic Fibrosis our focus

Orkambi has been shown to slow decline in lung function by 42%<sup>4</sup> and cut the number of infections requiring hospitalisation by 61%.<sup>5</sup> This gives people more control over their lives and greater quality of life.

Yet people with cystic fibrosis in Wales cannot access Orkambi. It has been two years since the licence of Orkambi. Orkambi is available to all eligible patients in Austria, Denmark, France, Germany, Luxembourg, the Netherlands, Italy, Ireland, Greece, and the United States.

In July 2016, NICE announced they were unable to recommend the drug due to its cost, despite acknowledging the drug is “important and effective”.<sup>6</sup> Since then, we have relentlessly called for negotiations and a fair, sustainable pricing deal for Orkambi. However, there has been no progress. People with cystic fibrosis are still waiting whilst their health and quality of life declines.

#### **4. Using the UK CF Registry to deliver a fair deal**

**We urge the assembly to consider how the UK CF Registry could form part of a robust and fair access scheme bridging the uncertainty gap associated with these medicines.**

The UK CF Registry is sponsored and managed by the Cystic Fibrosis Trust. The UK CF Registry offers population level coverage for people with cystic fibrosis in the UK. Anonymised, aggregated data from the registry are used as the evidence base for commissioning NHS care and post-marketing pharmacovigilance for the European Medicines Agency (EMA).<sup>7</sup> This means that it is possible to keep track of the effectiveness of Orkambi and other precision medicines to aid long-term monitoring.

In reimbursement decisions, the UK CF Registry could offer real world evidence of efficacy using observational comparative cohort models. The UK CF Registry already uses these models to assess the real-world efficacy of Ivacaftor in a study for the European Medicines Agency (EMA).<sup>8</sup>

This available data could inform a fair deal that secures access to transformational medicines for people with cystic fibrosis – now and in the future.

#### **5. Response to the Cabinet Secretary for Health and Social Care**

In his letter Health Minister Vaughan Gething states:

‘The NICE independent appraisal committee found that when compared to the current standard of care, the clinical benefit offered was modest and comes at a considerable cost’.

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<sup>4</sup> <http://www.businesswire.com/news/home/20161027005917/en/>

<sup>5</sup> <https://www.nice.org.uk/guidance/ta398/documents/appraisal-consultation-document>

<sup>6</sup> <https://www.nice.org.uk/guidance/ta398/documents/html-content-2>

<sup>7</sup> Data Resource Profile: The UK Cystic Fibrosis Registry, Taylor-Robinson D, University of Liverpool. 2017.

<sup>8</sup> [http://www.ema.europa.eu/docs/en\\_GB/document\\_library/EPAR\\_-\\_Assessment\\_Report\\_-\\_Variation/human/002494/WC500198918.pdf](http://www.ema.europa.eu/docs/en_GB/document_library/EPAR_-_Assessment_Report_-_Variation/human/002494/WC500198918.pdf)

# Cystic Fibrosis our focus

However, the data available at the time of NICE appraisal was from two short-term studies of 24 weeks. We now have long-term 96-week study data from which Orkambi has been found to slow decline in lung function by 42% and cut the number of infections requiring hospitalisation by 61%. These are significant outcomes not previously considered in the original appraisal.

Mr Gething also refers to a 'patient access scheme with Vertex Pharmaceuticals' which is 'available in the Welsh NHS, where clinically appropriate.' Whilst we welcome compassionate use of Orkambi in Wales, only the sickest patients are eligible to be considered when significant damage has already been done. We need a system which gives everyone with cystic fibrosis the earliest chance to access these medicines as soon as they are available and before irreparable lung damage has occurred.

The Cystic Fibrosis Trust is aware that meetings between Vertex and NHS Wales have been taking place since June and are ongoing to discuss a possible deal around a portfolio approach, which could look to incorporate Orkambi and potentially future treatments for CF. We welcome these discussions but emphasise that a resolution needs to be reached urgently.

## **Case study one- Rhian Barrance, 31 from Cardiff**

One of my closest friends, Jen, gave birth to a beautiful baby boy called Lorcán. Everyone who meets him falls in love with him immediately – he is bright, inquisitive and has Jen's gorgeous big brown eyes. But Lorcán needs more help and support than most children. Ten days after he was born he was diagnosed with cystic fibrosis. His extraordinary parents have launched themselves into doing everything they could to keep him as healthy and happy as they can.

I knew nothing about cystic fibrosis at the time, and spent a lot of time reading about it to figure out how I could best help and support Jen. When I found out about Orkambi, I threw myself into campaigning and it was then that I realised that there was something I could do – I could fight for the potentially life-changing treatments which target cystic fibrosis at its root cause to be made available to everyone in Wales who could benefit from them. This is why I started the e-petition to push for a debate in the Welsh Assembly to be considered.

Those who are currently eligible need access to it now as their health is deteriorating by the day. Lorcán and other children need Orkambi to be available to them as soon as they are old enough to take it. The National Assembly for Wales has made a strong commitment to children's rights through the Rights of Children and Young Persons (Wales) Measure (2011). One of the guiding principles of the United Nations Convention on the Rights of the Child (UNCRC) is the right to life, survival and development (article 6). Wales is often at the forefront in matters of children's rights, and providing children with a drug that can limit the lung damage caused by cystic fibrosis is a key part of realising the rights of children with the condition.

Ever since Lorcán was diagnosed with cystic fibrosis, he has faced a daily regime of treatment to manage his lung decline. These treatments do not address the underlying causes of the disease, and Lorcán's lung capacity will continue to decline despite the burden of constant drugs and physiotherapy. It is very difficult to accept that there is a treatment which could radically reduce the lung decline of people with this cruel condition, that is not available in Wales. It is particularly difficult to accept when this drug is available in many other countries, but this success abroad is an exciting prospect which gives us hope and makes me more determined than ever to keep up this fight.

# Cystic Fibrosis our focus

I urge the petitions committee to enable a debate to go ahead in the assembly to highlight the plight of those adults and children who cannot access this drug and to call for a solution that will allow urgent access to this life-changing drug in Wales.

## **Case study two- Beth Clarke, 36 from Cardiff**

I'm 36 years old and want to look forward to my future with my husband, but a huge chunk of each day is taken up by a regime that I must do to stay well, reminding me that I have a life-shortening genetic condition-cystic fibrosis (CF). My morning schedule of inhaled nebulisers and physiotherapy takes two-and-a-half hours in a grueling routine to stay alive, all before I can reach for a cup of tea. Using a machine to exercise my airways enables me to take deep breaths that my body wouldn't otherwise allow.

Coughing and spluttering my way through the day, I take upwards of 40 tablets and try to fit in half an hour of exercise to maintain as good health as I can. Despite this vigorous set of daily tasks, it is clear that I am battling with the symptoms-chest pain, shortness of breath, fatigue and not to mention the sickness that can accompany courses of intravenous antibiotics every six weeks. I'm doing my best and my family and I stay as positive and hopeful as we can- a mantra my parents have instilled in me- but I'm not tackling my cystic fibrosis at its core in a way that precision medicines like Orkambi would be able to do. My efforts are sometimes just not enough and my health can quickly deteriorate.

A treatment that could dramatically change my life for the better is something I have always talked and dreamed about with my parents and yet now that Orkambi is within touching distance I have to remind myself not to get my hopes up too much until it is available in Wales. It is incredibly cruel for all of us, knowing that Orkambi is available in countries across the world when our fight continues.

I urge the Welsh Assembly to debate this issue. I don't want my family and friends to be faced with another battle for medicines that could so easily change my life and the lives of others with cystic fibrosis. Please end the wait and give us hope again.

# Agenda Item 3.1

## P-04-667 – A Roundabout for the A477/A4075 Junction

This petition was submitted by Pembroke Town Council, having collected 115 online signatures and 482 paper signatures.

### *Text of the Petition*

*We call on the National Assembly for Wales to urge the Welsh Government to replace the Fingerpost Junction on the A477/A4075 with a roundabout – The current road configuration has not resolved the problems on this dangerous stretch of road.*

### **Assembly Constituency and Region**

- Carmarthen West and South Pembrokeshire
- Mid and West Wales

**P-04-667 Roundabout for the A477/ A4075 Junction – Correspondence from the petitioner to the Committee, 15.12.17**

Good Afternoon Kathryn

Thank you for your email. The response from the committee and the final stage 4 document was discussed at a recent meeting of Pembroke Town Council on Thursday 7th December.

I have been asked to write to you to express Councils deep disappointment with the findings of the document. The report actually states that the Accident rate has increased, and I quote " **There has been an increase in the total number of collisions per year in the "After" period compared with the average for the three years in the Before period. In addition there has been an increase in the number of collisions involving a right turning vehicle emerging from the A4075 failing to give way to a westbound A477 vehicle**". so obviously it is not doing what it is supposed to do, and in our opinion the only way forward is the installation of a roundabout, and urge you to reconsider this position.

We have now written to Valero and David Saunders Haulage which uses this junction on a regular basis, so we can report to you their findings.

We quote again this is a dangerous junction, and is an accident waiting to happen, and will keep pointing this out again and again and will hold them responsible for the next death that will occur if the layout of the road stays the same.

I would be grateful if you could forward the above to be included for the Agenda on 9th January, and will try my best to forward further correspondence to you by the 2nd.

Kind Regards

*Suzie Thomas*  
*Town Clerk – Pembroke*

# Agenda Item 3.2

## **P-05-722 Protect Special Educational Needs.**

This petition was submitted by Nicola Butterfield, having collected 553 signatures.

### **Text of the Petition**

We call upon the National Assembly for Wales to urge the Welsh Government to ensure that spending on the provision of special educational needs is ringfenced, recognising that this is an investment in the children of Wales, and that local authorities should be directed to ensure that adequate levels of funding are available so that those children who require such services are able to go on and live happy and fulfilled lives, while their families are not left to contend with the fear of competing with one another for placements.

### **Assembly Constituency and Region:**

Aberavon

South Wales West

# Agenda Item 3.3

## **P-05-787 Save the Future Generation of Wales**

This petition was submitted by Ken Ebihara having collected 54 signatures online.

### **Petition text**

We the undersigned call on the National Assembly for Wales to urge the Welsh Government to ensure the financial resources for youth work contributed by the individual local authorities through 'Revenue Support Grant' is at least 50 percent of its notional allocation.

### **Additional information**

The matter of whether or not introducing the hypothecation of 'Revenue Support Grant' (RSG) for youth work has already been identified in one of the reports released by the 'Children, Young and Education Committee' in the last year. It is a fact that there is a gap between the actual financial contributions to youth work provided by the individual local authorities through 'RSG' and that of the notional allocation for youth work. It is crucial to assure and maintain the quality of youth work provided to young people in Wales in order for them to gain the precious opportunities to improve themselves in a supportive environment. This crucial factor should not only depend on the individual local authorities' decisions, which differ from one to another due to their own priority of expenditure. More proactive intervention by the Welsh Government must be required to ensure the minimum level of quality of services provided all across Wales. Introducing partial hypothecation prevents the individual local authorities from reducing further reduction in financial resources spending on youth work, while it also enables them to retain some extent of autonomy to prioritise their needs of expenditure in accordance with their individual priorities. This particular notion could be the most realistic solution for the matter.

### **Assembly Constituency and Region**

- Cardiff Central
- South Wales Central





Eich cyf/Your ref P-05- 787  
Ein cyf/Our ref EM/05158/17

David John Rowlands AM  
Chair  
Petitions Committee

SeneddPetitions@assembly.wales

January 2018

*Deu David,*

Thank you for your letter dated 12 December 2017 concerning the review of Extending Entitlement, and the level of spend on youth work provision from the standard spending assessments.

I can confirm that the future of youth work, including funding, was considered as part of the review of Extending Entitlement. Having recently received the report from this review it is important that I take some time to reflect on the findings before committing to a course of action. In the meantime I have asked the Youth Work Reference Group, which is made up of sector experts and representatives as well as Welsh Government officials, to consider the report, and advise on next steps. This will inform my decision on the way forward, and what further consultation should take place. I can assure you that future arrangements for youth work and funding for services will be part of any future public consultation that takes place.

I can also advise that a notional 1% (£21.9 million) of the total standard spending assessment is allocated to youth work. The decision on how to spend their budget lies with the local authorities in line with their identified priorities.

*Cofion gorau*  
*Eluned Morgan*

**Eluned Morgan AC/AM**  
Gweinidog y Gymraeg a Dysgu Gydol Oes  
Minister for Welsh Language and Lifelong Learning

Bae Caerdydd • Cardiff Bay  
Caerdydd • Cardiff  
CF99 1NA

Canolfan Cyswllt Cyntaf / First Point of Contact Centre:  
0300 0604400

[Gohebiaeth.Eluned.Morgan@llyw.cymru](mailto:Gohebiaeth.Eluned.Morgan@llyw.cymru)  
[Correspondence.Eluned.Morgan@gov.wales](mailto:Correspondence.Eluned.Morgan@gov.wales)

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

**Pack Page 73**

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

**P-05-787 Save the Future Generation of Wales – Correspondence from the  
Petitioner to the Committee, 14.01.18**

Thank you very much for the opportunity to respond to the current debate on my petition.

Firstly, I am very pleased with the fact that the financial aspect of youth work has been included as a part of the reviewing process of Extending Entitlement and the involvement of the Youth Work Reference Group in the process including clarifying the contents of public consultation. As it is emphasised in the latest two correspondences of the Minister for Welsh Language and Lifelong Learning, it is important to clarify the current circumstances and consider how the Welsh Government creates policies and strategies for youth work with an effective approach. The establishment of a new National Youth Support Services Board would be seen as a wholistic approach as the Board would not only be responsible for financial aspect of youth work, but also implement the reviewing process of Extending Entitlement and shape the National Youth Work Strategy when it is established. Considering these elements, I would like the committee to allow the Minister to spend sufficient amount of time to find the most effective way for supporting young people in Wales.

Secondly, I am satisfied that the committee is now informed by the Minister of a fact that £21.9 million, which is equivalent to 1% of total standard spending assessment, was allocated to youth work in Wales. I also confirmed the fact above with a document, 'Welsh Local Government Revenue Settlement 2017-2018 Background Information for Standard Spending Assessments'. It is stated on page 21 that £21,932,000 was allocated to youth work service between 2017-2018 with Indicator Based Assessments (IBAs). I personally regard that it is quite meaningful for the committee to understand how much financial resources are currently spent

on youth work in Wales in a large picture for the further consideration on my petition.

# Agenda Item 3.4

## **P-05-742 Stop Forsythia Closing!**

This petition was submitted by Forsythia Youth Centre, having collected 74 signatures. The petition has also collected 533 signatures on an alternative e-petition website.

### **Text of the Petition**

Forsythia Youth Centre is at risk of closing due to the uncertainty surrounding Welsh Government's Communities First funding. Forsythia Youth Centre is a FREE access youth provision which is open: –

- 4 nights a week for 51 weeks of the year;
- Open during the day and the evenings throughout school holidays;
- Open on the weekend if completing project work.

Without fail, Forsythia has a minimum of 50 young people aged 11–20 from across Gurnos, Galon Uchaf, Pant, Dowlais and Penydarren, attending every night. Without Forsythia Youth Centre, young people would not have a safe place to access within their community and they would not have anywhere else to go due to a lack of other provision aimed at young people.

Forsythia Youth Centre offers young people the opportunity to take part in youth projects, such as 'Commit to Quit' with Ash Wales, Erasmus+ project on 'Attitudes and Values of Youth Work', and the 'Agenda Project' with Cardiff University. Young people are also provided the opportunity to access organisations such as Drug Aid, Sexual Health projects, Smoking Cessation, Mental Health and Confidence Building, Skills and Qualifications and receive in house support from qualified youth workers.

Young people and the workers are very concerned about the uncertainty surrounding the Communities First funding, as without this funding, Forsythia will have to close down.

We call on the National Assembly for Wales to urge the Welsh Government to ensure that potential changes to the Communities First programme do not cause the closure of Forsythia Youth Centre.

### **Additional Information**

1. The young people involved with Forsythia Youth Centre have been part of a campaign to improve community safety, which resulted in having a zebra crossing installed outside of the Youth Centre, lighting installed on the hospital pathways and the dangerous subway closed which was always full of drug paraphernalia.
2. The young people are involved with going into local schools and Merthyr Tydfil College to deliver peer education on Smoking Cessation.
3. The young people of Forsythia have been involved with the National Assembly for Wales Health and Social Care Committee during the Forth Assembly, where young people took part in a focus group meeting with Assembly Committee Members on the new Psychoactive Substances Inquiry.
4. The Forsythia Youth Centre has won 18 awards over the past 13 years both locally, nationally and internationally.
5. Young people at Forsythia have collected 533 signatures using change.org to support this petition.

**Assembly Constituency and Region.**

- Merthyr Tydfil and Rhymney
- South Wales East



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Merthyr Tydfil, CF47 8AN

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Croesawn ohebu yn Gymraeg a fydd gohebu yn y Gymraeg ddim yn arwain at oedi.

Rhowch wybod inni beth yw'ch dewis iaith e.e Cymraeg neu'n ddwyieithog

We welcome correspondence in Welsh and corresponding with us in Welsh will not lead to a delay.

Let us know your language choice if Welsh or bilingual.

Croesawn alwadau yn y Gymraeg  
We welcome calls in Welsh

Mr David J Rowlands AM  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NT

Dyddiad/Date: 27<sup>th</sup> November 2017

Ein Cyf./Our Ref.: 17 11 27 (L) DR/GC  
Eich Cyf./Your Ref.:

Gofynnwch am/Please ask for: **Gareth Chapman**  
Linell Uniongyrchol/Direct Line: **(01685) 725000**  
e-bost/email: **chief.executive@merthyr.gov.uk**

Dear Mr Rowlands

## **FORSYTHIA YOUTH CLUB - 3G'S DEVELOPMENT TRUST**

Thank you for your enquiry regarding the future of the Forsythia Youth Centre in the current Communities First North Cluster of Merthyr Tydfil. My officers have been working with the community throughout the year to minimise the impact of the closure of the Communities First programme where possible. As stated in our previous correspondence, current provision at Forsythia Youth Club was scheduled to remain in place until the full closure of this Welsh Government programme, in line with the delivery plan submitted to Welsh Government.

In preparing for the Legacy fund my officers have been working closely with elected members and colleagues across the third sector, as well as engaging with the public, to identify the communities priorities. We are committed to ensuring that services which may receive financial support through the Legacy arrangements meet both localised needs as well as being in line with needs of our overall Wellbeing Assessment of the County Borough of Merthyr Tydfil.

Having undertaken this work elected members very recently (22/11/17) received a report on the future legacy options and after significant deliberation agreed a suite of proposals for the allocation of this funding. Individual organisations, which include the 3G's Development Trust, will now be engaged in order to develop service specifications, in line with the funding available. In relation to the 3G's Development trust this will include the continuation of Youth provision on the Gurnos estate 'Forsythia'.

Gareth Chapman CStJ., DL., LL.M., MBA., CMgr., DipLG., CCMI., Solicitor  
Chief Executive/Prif Weithredwr

The decisions of the Council on future funding, through the Legacy arrangements, is in the process of being formally communicated to those organisations involved in the delivery of the current Communities First programme.

It is unavoidable however that there is going to be some concerns across the communities as the funding available is extremely limited, in comparison to the previous resources available and therefore can only meet a small number of the priorities which were considered.

If we can be of any further assistance please do not hesitate to contact me.

Yours sincerely



**Gareth Chapman**  
**Chief Executive**

# Agenda Item 3.5

## **P-05-766 Make a Vegan Option Compulsory In Public Canteens**

This petition was submitted by Rachel Turnbull, having collected 118 signatures online.

### **Petition text:**

We call on the National Assembly for Wales to urge the Welsh Government to make including a vegan option obligatory for all public canteens or services in Wales where they have the powers to do so.

The Portuguese Parliament has approved an obligatory vegan option in all public canteens (e.g. schools, universities, prisons, hospitals) – a huge step for vegan catering for all. Over 5% of the population is vegan and growing. A vegan diet is healthier, it conserves resources and protects the planet, above all it's cruelty free. United Nations has called upon us to consume more plant based foods. Animal products are linked to the increase in cancer and heart disease.

### **Assembly Constituency and Region**

- Newport West
- South Wales Central



# Agenda Item 3.6

## **P-05-764 Better Mental Health Services for Adults**

This petition was submitted by Megan Tudor, having collected 84 signatures online.

### **Petition text:**

We call on the National Assembly for Wales to urge the Welsh Government to improve the treatment of adults in mental health services with particular focus on improving services in the community such as CMHT, inpatient, A&E and ambulance services.

Too often the mental health services have failed adults. It is appalling to think that everyday thousands of adults are being turned away when begging for help. To be admitted to hospital and quickly reviewed by a psychiatrist and being told 'just distract yourself you'll be fine' and sent home.

I understand that there have been major cuts to these services over the last few year, but frankly it is unacceptable. There should not be a price on someone's mental health. Mental health should have the same level of care as physical health.

Why is there more support in place for children suffering from mental health? Children have support in place following hospital admissions but there's nothing for adults. There may be promises that they will receive support from certain services but they quickly fall through. I am disgusted by the horror stories I have heard from people in the system. I have witnessed first hand the lack of care provided for adults suffering from ill mental health. This needs to change and it needs to change fast. I will no longer sit back and watch this happen.

I want to see huge changes in the way adult patients are treated and supported. All services should liaise with each other to provide the best care possible. At the moment communication is lacking between services leaving the patient without support. If emergency services are needed then there needs to be some follow up support in place for when they return home. Most services work within the hours of 9am and 5pm but mental health doesn't go away at 5pm we need more accessible after hours support. I want to see more care from staff too, they may have the training required for their position but empathy and respect is nowhere to be found. It's time to change.

### **Additional information:**

Ok let's talk..

Mental Health can still be quite a taboo topic but I want you to stick with me here for a minute. I just want you to imagine feeling completely lost, empty and like you have no reason to live. You want the pain to end so you take the most difficult step of your life; you ask for help. You just want someone to recognise how much pain you're in and make it go away.

The doctors/paramedics/police/psychiatrist tell you it's 'nothing to worry about you must be having a bad day that's normal'. The truth is it's not just a bad day you've been stuck in this dark place for much longer. They don't listen, you go home and although you didn't think it was possible, you feel worse than you did before asking for help.

**THIS ISN'T HOW IT'S SUPPOSED TO BE!** The help and support should be readily available for those that need it but it's not and that's what needs to change. If this petition works it could save thousands of lives every single day. Please show your support by signing this and share it. Things have got to change.

#### **Assembly Constituency and Region**

- Montgomeryshire
- Mid and West Wales

# Agenda Item 3.7

## **P-05-784 Prescription drug dependence and withdrawal – recognition and support**

This petition was submitted by Stevie Lewis, having collected 213 signatures online.

### **Petition text:**

We call on the National Assembly for Wales to urge the Welsh Government to take action to appropriately recognise and effectively support individuals affected and harmed by prescribed drug dependence and withdrawal.

This petition has been set up to raise awareness of the plight of individuals in Wales who are affected by dependence on and withdrawal from prescribed antidepressants and benzodiazepines – and specifically to ask the Welsh Government to support the BMA's UK-wide call for action to provide timely and appropriate support for individuals affected.

The term "prescription drug dependence" refers specifically to the situation where, having taken their antidepressant or benzodiazepine medication exactly as prescribed by their doctor, patients find they are unable to stop because of the debilitating withdrawal effects. It is important to note here that addiction and dependence are related but different issues. Use of the term addiction implies pleasure seeking behaviour. Reporting of prescription drug dependence in the media continues to allude to "misuse" and "addiction" as if the patient is responsible in some way for their own harm. This is far from the truth. There is no pleasure whatsoever in finding that if you try to reduce or stop your antidepressant, you suffer a wide range of physical and emotional disturbances, that for some people can be life limiting and, tragically, even life ending. Patients need formal acknowledgement, support and guidance to help them through their withdrawal journey and this currently does not exist.

### **Additional information:**

The British Medical Association has recently highlighted the issue of prescribed drug dependence. In May 2017, they wrote: "Prescribing of psychoactive drugs is a major clinical activity and a key therapeutic tool for influencing the health of patients. But often their use can lead to a patient becoming dependent or suffering withdrawal symptoms. In the absence of robust data, we do not know the true scale and extent of the problem across

the UK. However, the evidence and insight presented to us by many charity and support groups shows that it is substantial. It shows us that the 'lived experience' of patients using these medications is too often associated with devastating health and social harms. This represents a significant public health issue, one that is central to doctors' clinical role, and one that the medical profession has a clear responsibility to help address." Because the side effects, tolerance effects and withdrawal effects of these medicines are not medically recognised for what they are, when patients develop these related effects/symptoms they are often prescribed other medicines and then polypharmacy complicates the problems further.

Affected patients are finding themselves with vague diagnoses eg: 'medically unexplained symptoms' or 'functional/somatic system disorders'. These are essentially psychiatric diagnoses attributing various debilitating and disabling physical symptoms to patients' own anxiety, beliefs, etc. This has the effect of discounting, disempowering and demoralising these patients still further. If it cannot be acknowledged that patients can have sustained functional nervous system dysfunction and damage as a consequence of taking medicines 'as prescribed' (sometimes over many years), systemic medical learning and improvement is stifled and patients continue to be further harmed. Meanwhile the initial prescribing risks remain severely underestimated and misleading prescribing guidelines and 'best practice' advice is unchanged.

#### **Assembly Constituency and Region**

- Monmouth
- South Wales East

Vaughan Gething AC/AM  
Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau  
Cymdeithasol  
Cabinet Secretary for Health and Social Services



Llywodraeth Cymru  
Welsh Government

Our ref VG/05382/17

David John Rowlands AM  
Chair - Petitions Committee  
National Assembly for Wales  
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4 January 2018

Dear David,

Thank you for your letter of 12 December on behalf of the Petitions Committee concerning Petition P-05-784: Prescription drug dependence and withdrawal - recognition and support. I shall respond to the specific points you have highlighted.

- **whether antidepressants should be added to the list of drugs targeted for reduction by the All Wales Medicines Strategy Group;**

As you are aware there are clear guidelines in place from the National Institute for Health and Care Excellence (NICE) for the prescribing of antidepressant drugs and the treatment of depression. Comprehensive guidance on the prescribing and monitoring of hypnotics and anxiolytics, including benzodiazepines were published by the All Wales Medicines Strategy Group in 2011 and updated in 2016. This includes guidance on prescribing and reduction/tapering over time.

Clinicians are required to follow these guidelines and use their clinical judgement in determining what course of treatment to prescribe to their patients, based on their patients' individual needs and medical history. The options for treatment include psychosocial interventions in addition to or as an alternative to prescribed medication.

Depression can be linked to the presence of chronic physical illness as well as deprivation; in some areas of Wales there is a high burden of such problems. Also, debt can lead to increased levels of stress and anxiety, to physical and mental health problems such as depression, low self esteem and relationship breakdown and even to loss of employment, which can lead to increased levels of mental ill health. Prescribing antidepressants is one aspect of helping patients manage their condition and reducing access to these medicines by requiring fewer prescriptions to be issued could be too simplistic an approach.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

Nevertheless, my officials will investigate the scope and need for any further guidance over and above that already published by NICE and the degree to which a national prescribing indicator might support clinical decision-making.

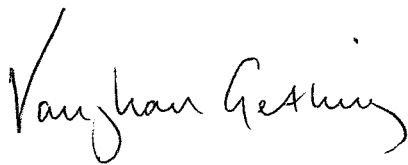
- **whether patients across Wales should have access to a Prescribed Medication Support Service.**

Tackling dependence on prescription only medicines and over the counter medicines is a priority for this government. Our Substance Misuse Delivery Plan 2016-18 contains a number of specific actions in this regard. This includes targeted prevention and awareness raising campaigns and the development of a specific Substance Misuse Treatment Framework (SMTF) focusing specifically on prescription only medicines and over the counter medicines. This guidance, expected to be published in March 2018 will assist our seven Substance Misuse Area Planning Boards (APBs) to commission and deliver treatment services to support those who are dependent on a range of drugs, based on the identified need in their areas.

You may also wish to be aware that help and support is available through DAN247, a free and bilingual telephone drugs helpline providing a single point of contact for anyone in Wales wanting further information or help relating to drugs (including prescription drugs) or alcohol and provides information on services available in their local areas. Individuals can access it on 0808 808 2234 or by visiting [www.dan247.org](http://www.dan247.org).

Thank you again for writing to me on this matter. I hope my response is helpful.

Yours sincerely,



**Vaughan Gething AC/AM**

Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau Cymdeithasol  
Cabinet Secretary for Health and Social Services

**Second submission in response to the letter from the Cabinet Secretary for Health and Social Services dated 04 January 2018**

**TO EFFECTIVELY SUPPORT PATIENTS WITH PRESCRIBED DRUG DEPENDENCE**

I am going to address the points in reverse order, and focus first on addressing the subject of appropriate help for those who have already been harmed by prescribed drug dependence (PDD). Mr Gething has not answered your question. You may have noticed that his letter is broadly a rehash of what the previous Minister, Rebecca Evans said. I don't see what more I can do in addition to my previous submission other than stand on the rooftops with a megaphone and shout: "We have not misused. You are neither recognising what has happened to us nor supporting our recovery."

In support of my frustration I would urge you to scan through the document to which Mr Gething refers (Substance Misuse and Delivery Plan 2016–18)<sup>1</sup> and see where you think policy statements are made regarding plans to help those whose health has been damaged from taking prescription drug medication in line with their doctor's advice. It is a document about misuse.

To repeat myself from my last submission, I recognise that it suits the Welsh Assembly government to chunk this issue up into an overall heading of "Substance Misuse", but I will say again that it is damaging and inhuman to do so and hides a truth that I believe people need to be aware of. The word "stigmatising" is bandied liberally around the subject of mental health but I am inclined to use that word here. Forcing patients who have been harmed by drugs that they took under their doctor's advice under the umbrella of "substance misuse" is stigmatising and branding them inaccurately and unjustly, and will continue to result in patients not getting the help they need. It is only right and proper that PDD is openly acknowledged, appropriately resourced and supported, and there is already a team in place in North Wales that can provide a template of care. That template of care differs from the service provided for street drug misuse or POM/OTC misuse. I am requesting the setting up of a separate arm to achieve that aim Wales-wide, funded from the "almost £50 million annually" available as stated by Ms Evans in November 2017.

**TO APPROPRIATELY RECOGNISE PRESCRIPTION DRUG DEPENDENCE**

I am pleased to read that the Cabinet Secretary for H&SS will ask his officials to investigate the scope and need for further guidance over and above that already in existence for antidepressants.

This may mean that the Committee considers their work to be done in the case of this aspect of my petition. I would like to take the opportunity to urge you to continue to press Mr Gething to agree to treat antidepressants, especially SSRIs and SNRIs, with the same caution as is currently applied to hypnotics and anxiolytics. It is extremely likely that members of the Committee will know someone in their family or amongst their friends who takes an antidepressant. It is their health and care we are talking about here too.

To quote from Johann Hari's book: *The Lost Connections: Uncovering the Real Causes of Depression – and the Unexpected Solutions* Bloomsbury (2018)<sup>2</sup>

*“To me, this seems like the most crucial piece of evidence about antidepressants of all: most people on these drugs, after an initial kick, remain depressed or fully depressed again. Only one in three of the people who stayed on the pills had a lasting, proper recovery from their depression. (And even that exaggerates the effect— since we don't know how many of those people would have recovered naturally without the pills.)”*

From *The Emperor's New Drugs: Exploding the Antidepressant Myth* by Irving Kirsch Random House (2009)<sup>3</sup>

*“Formerly depressed patients are far more likely to relapse and become depressed again after treatment with antidepressants than they are after psychotherapy. As a result, psychotherapy is significantly more effective than medication when measured some time after treatment has ended, and the more time that has passed since the end of treatment, the larger the difference between drugs and psychotherapy. This long-term advantage of psychotherapy over medication is independent of the severity of the depression. Psychotherapy outperforms antidepressants for severely depressed patients as much as it does for those who are mildly or moderately depressed.”*

Mr Gething states a reduction in prescribing of antidepressants is a simplistic approach. I would maintain that actually it is extremely difficult and divisive, which is why there are so many of us campaigning to bring this issue to the attention of our various governments. If it were simple, I wouldn't have had to raise a petition and be using this democratic means of getting my voice heard on behalf of the people who have been harmed by antidepressants. Here are some of the reasons why the treatment of people for depression with antidepressants, particularly SSRIs and SNRIs, is a difficult subject to address and why there will inevitably be resistance to the request for a targeted reduction in prescribing.

Firstly, because politicians are being advised by members of the medical profession who consistently sell the benefits of these drugs and downplay the risks. They lend their ears



to professors with medical degrees and strings of letters after their names who are compelling in their insistence of the drugs' safety and efficacy, and that withdrawal (or "discontinuation", the euphemism of choice) is short term. The evidence they turn to is provided by the pharmaceutical companies who hide clinical trials showing harm and provide ghost-written articles, provided by their marketing departments, to medical journals promoting their benefits. This system is described at length by Dr David Healy in his book *Pharmageddon*<sup>4</sup>. This is the system in place that regularly and persistently drowns out the voices of people who have found themselves physically dependent on antidepressants and unable to withdraw, or find themselves in the hell of withdrawal. I fear that any expert brought in to speak to you in support of the safety and efficacy of these drugs will undoubtedly convince you, and yet again we will be ignored. We fervently hope that via our petitions, this one and the sister petition raised in Scotland, which I will come on to later, you will take us seriously and help us bring about the change that we feel is needed.

We are forced to ask – since when does "science" and "evidence" trump people's experience to the point where we are disbelieved and ignored, and what is the Welsh government going to do to help us? This is not a black or white issue. Yes, of course there are people who say they have been helped by antidepressants. Yet surely it is entirely appropriate for us to ask for specific help for those who say they have been hurt by them, and insist on a means to be put in place to reduce the number of people being hurt in the future.

Secondly this subject is difficult and divisive because the rationale for the use of antidepressants is based on shaky evidence and the medical profession does not want to openly acknowledge this. When challenged the medical profession says that antidepressants are prescribed in the growing numbers that they are because the benefits outweigh the risks. Medicines are licenced for use in the UK by the Medicines and Healthcare Products Regulatory Agency (MHRA). The MHRA licences a drug based on the scientifically proven benefits. When pressed by author, researcher and campaigner Bob Fiddaman for a list of the benefits of fluoxetine (Prozac), on November 24<sup>th</sup> 2016, the MHRA stated in their reply to him: "*.....benefits are considered to be the therapeutic effects of the product to improve the medical conditions for which a product licence has been granted..... In the case of fluoxetine, it raises the level of the neurotransmitter, serotonin, in the brain which can improve symptoms of depression*"<sup>5</sup>

The MHRA has a Yellow Card System where doctors can report adverse effects – the risks associated with each drug. The Yellow Card system has a list of 27 "Disorders" reported for the SSRI fluoxetine (Prozac)<sup>6</sup>, including Cardiac, Ear and Labyrinth, Endocrine, Eye, Gastrointestinal, General, Metabolism and Nutritional, Musculoskeletal and Connective Tissue, Nervous system, Psychiatric, Skin, Vascular. The list for paroxetine, marketed as

Seroxat, the drug I took, is similar. Most of the people who experience adverse effects and withdrawal on SSRIs will have one, usually more, of those listed. I had 7 of the list above in withdrawal and still have 3 post withdrawal. These are the risks when taking an antidepressant. The only benefit the MHRA can cite is: “... *it raises the level of the neurotransmitter, serotonin, in the brain which can improve symptoms of depression*”.

The Yellow Card system for antidepressants is vastly underused because when a patient reduces or stops their antidepressant, the ensuing symptoms are diagnosed by the GP as being a relapse of their illness rather than a reportable adverse or withdrawal effect. The only way that the medical profession can “know” that antidepressants work is based on some of their patients telling them, in their opinion, they feel better. So why is it, then, when their patients tell them they feel worse, that opinion is not equally ascribed to the drug? Why is the diagnosis relapse not withdrawal?

*“We also have to ask do antidepressants worsen outcomes for patients? A 2011 meta-analysis by McMaster University in Canada discovered: “Patients who use antidepressants are much more likely to suffer relapse of major depression than those who use no medication at all.” How many of these patients have been misdiagnosed and may in actual fact be suffering not from relapse but withdrawal? ”*

From the 1970’s until recently, patients were told that their depression/anxiety is due to a chemical imbalance in the brain which is corrected by the antidepressant. This is the basis on which I was prescribed Seroxat in 1996 for intermittent insomnia and PMT. There is no scientific evidence to date to prove this. Today the explanation from the Royal College of Psychiatrists is that depression/anxiety is due to inflammation in the brain which is corrected by the same drugs. To date there is no scientific evidence to prove this. Should this theory be proved, logic dictates that anti-inflammatory drugs are likely to be the correcting drug of choice, not neuro-toxins which change the way neurotransmitters are used in the brain. Anti-inflammatories have strong scientific evidence to prove their efficacy.

If 64 million prescriptions for diabetics had been written in 2016 based on no sound scientific evidence and with the side and adverse effects listed above, there would be a public outcry.

Finally, this subject is difficult and divisive because GPs have nothing else in their armoury to offer due to the lack of readily available alternative therapies and the last thing they want to admit openly is the only thing they have to offer causes some people harm. Experts Dr David Healy, Dr Terry Lynch and Dr Noel Thomas have written to you directly to express their concerns. I’ll leave the last word to Professor John Read:

*“Our survey of 1800 antidepressant users, the largest ever, found that one in four were addicted and 55% experienced withdrawal symptoms when trying to stop or reduce. Meanwhile the drug companies and Royal College of Psychiatry insists they are not addictive. This is a repeat of the years of denial that benzodiazepines are addictive. And antidepressants are no more effective than placebo for about 90% of people.”<sup>8</sup>*

## **THE SCOTTISH CAMPAIGN**

I wish to bring to the attention of the Committee that there is a sister petition to this in Scotland which has been running since May 2017. The harm done to the people of Scotland by PDD is the same as to the people of Wales. In Wales we are in a better position because we already have in place the targeted reduction of anxiolytics (benzos) and hypnotics (Z drugs/sleeping pills). Also we already have a small, geographically limited Prescribed Medication Support Service as described at length in my last submission.

It would be inspiring if the two Petitions Committees were prepared to collaborate on this issue and even more inspiring if the two Governments would collaborate and cooperate in providing the recognition and help we are seeking. The BMA and All Party Parliamentary Committee for PDD are waiting to hear from you!

The Scottish petition differs from the Welsh one in as much as they have already invited and received many submissions from people with lived experience of PDD. Some of their stories are heart-rending. Every word written applies to Wales as to Scotland. It is a problem which is no respecter of borders. These submissions are publicly available here:

<http://www.parliament.scot/GettingInvolved/Petitions/PE01651>

I hope you will also decide to allow others with lived experience to share their stories so you can learn more about the depth of the problem and the suffering PDD brings. (At the last minute I have received a submission on his ongoing experiences of PDD from James Moore which I would like to include today).

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**IAHIP Accreditation number:** ██████████

23<sup>rd</sup> December 2017

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**Re: Petition: Prescribed Drug Dependence and Withdrawal:**

I have been a practicing physician in Ireland for the past thirty-five years, fully registered with the Irish Medical Council. I am also a fully accredited psychotherapist. Having worked as a GP for over ten years, for the past seventeen years I have provided a recovery-oriented mental health service, attended by people from all over Ireland and beyond, including the UK. I am also a best-selling mental health author, and mental health educator. For nine years (2003-12) I was appointed by the Irish government to a series of national expert mental health groups, including the Expert Group on Mental Health Policy (2003-06) that formulated *A Vision for Change*, Ireland's official mental health policy document.

**This petition has my full support.** It is a responsibility of the medical profession to identify and publicly herald matters relating to public health, a duty generally executed well, with one notable exception – when the perceived welfare of the medical profession itself might be best served by either not noticing such an issue or remaining relatively silent about it. Prescribed drug dependence and withdrawal is one such issue. It is most regrettable that the medical profession has not only not taken the lead in this important matter, but has persistently resisted adequate public recognition of the extent and seriousness of the problem of prescribed drug dependence, including benzodiazepines and SSRIs.

**A long-standing systemic denial and failure.** The medical profession has consistently denied/minimised the extent of prescribed drug dependence. In 1998, the then head of Social Audit UK Charles Medawar wrote: “Over the past 200 years, doctors have prescribed an almost uninterrupted succession of addictive drugs, always in the belief that they would not cause dependence or that patients would be mainly responsible if they did. From alcohol and opium to barbiturates and benzodiazepine tranquillisers, all of these drugs have been prescribed as sedatives for mental distress.”<sup>1</sup>

The title of Medawar's article – “Antidepressants: Hooked on the Happy Drug” indicated his major concern regarding SSRI antidepressants and addiction/dependence – twenty years ago. In his 1992 book *Power and Dependence: Social Audit on the Safety of Medicines*, Charles Medawar wrote: “The evidence suggests that the providers of medicine keep making the same mistakes, mainly because they have been allowed to deny how badly things have gone wrong. Virtually every anti-anxiety drug and sleeping pill ever prescribed has proved to be a drug of dependence - yet each one has been prescribed, often for many years, as if the risk did not exist. This pattern of error has been established over the past 100 years or more, and continues to this day.”<sup>2</sup>

Alcohol, morphine, heroin, amphetamines, barbiturates, the benzodiazepines and the SSRI antidepressants were each, in their day, introduced as wonderful, non-addictive, non-dependency-creating treatments. The addictiveness of each of these drugs went unnoticed and/or vehemently denied by the medical profession for decades after they were introduced. Regarding each of these drugs, the medical profession has been painfully slow to accept their drug dependency-creating potential. The

push to have them recognised as addictive/dependency-creating in each case came not from within the medical profession, but from the public – as is happening here, in relation to this petition.

Throughout the decades, people had great difficulty convincing the medical profession that these drugs were addictive/dependency forming. In my 2001 best-selling book *Beyond Prozac*, flagging drug dependency problems with SSRI antidepressants I had repeatedly observed, I wrote: “Throughout history, millions of drug addicts have been created by the ‘best’ modern medical treatments of the day. Therefore, when doctors say that antidepressant drugs are not addictive, remember that they said precisely the same thing about a long list of addictive ‘treatments’. Based on the experiences of patients taking SSRI antidepressants, for many years I have believed that these drugs are addictive. Contrary to what you hear from psychiatrists and GPs, there is evidence suggesting that the newer antidepressants such as Prozac, Seroxat, Effexor and others may well be addictive. These drugs give an energy buzz, often making people feel better. But so did amphetamines and barbiturates, which were subsequently — many years and millions of patients later — found to be a very addictive group of drugs. I know many people who have had great difficulty coming off these newer antidepressant drugs.”<sup>3</sup>

In a 2001 article in the *Independent* entitled “World Health watchdog warns of addiction risk for Prozac users”, Professor Ralph Edwards (of the World Health Organisation’s unit monitoring drug adverse effects) expressed considerable concern that, with regard to the SSRI antidepressants, “the issue of dependence and withdrawal has become much more serious”.<sup>4</sup>

**Raising the addiction/drug dependence bar – the medical profession’s response to the benzodiazepine debacle:** The public – and the politicians who serve the public – might reasonably expect that the medical profession would have responded to the international benzodiazepine debacle – of addiction/dependence denial and failure to protect the public they serve – by increasing their awareness and vigilance in relation to prescribed drug dependence. The opposite was the case.

Produced in the wake of the benzodiazepine debacle, the SSRI antidepressants were not even tested for their addictive/drug dependency potential prior to being licensed for public consumption. Yet drug companies, psychiatrists and GPs alike felt it appropriate to unequivocally assure the public that these new substances were definitely not addictive or dependence-producing. UK psychiatrist David Healy, Professor of Psychiatry, Bangor University, Wales – a former secretary of the British Association for Psychopharmacology – has subsequently identified evidence of drug withdrawal problems within the original SSRI antidepressant drug trials.<sup>5</sup>

In 1980, the then current edition of the *DSM* (the *DSM-III*) – often referred to as the psychiatrist’s bible, which sets standards of psychiatric understanding and practice internationally – defined drug dependence as the presence of *either* tolerance (needing more of the drug to get the same effect) *or* withdrawal symptoms. Consistent with this definition of drug dependence, in 1990, according to the American Psychiatric Association, “The presence of a predictable abstinence syndrome following abrupt discontinuance of benzodiazepines is evidence of the development of physiological dependence”.<sup>6</sup>

In a subsequent edition, the *DSM-IV* (1994), the American Psychiatric Association changed the definition of drug dependence, making it *more* difficult to define drugs as addictive/dependency-creating. They now defined drug dependence as the presence of *both* tolerance and withdrawal. Rather than become *more* alert to the important issue of dependence to prescribed drugs as one might expect a responsible profession to do, the American Psychiatric Association both moved the goalposts and heightened the bar. As Charles Medawar subsequently commented, ‘This definition would exclude all but the most exceptional cases of dependence on benzodiazepines’.<sup>7</sup> This definition also results in the gross under-recognition of drug dependence problems with SSRI antidepressants.

The World Health Organisation’s view of drug dependence has contrasted with that of the American Psychiatric Association. According to the World Health Organisation, “When the person needs to take repeated doses of the drug to avoid bad feelings caused by withdrawal reactions, the person is dependent on the drug”.<sup>8</sup> Regrettably, this common-sense definition of drug dependence has been largely ignored by the medical profession.

**The current extent of the problem of prescribed drug dependency:** The two main drug groups of concern are the benzodiazepine tranquillisers and the SSRI antidepressants. Despite clear guidelines for over two decades that benzodiazepines should only be prescribed for one month or less due to drug dependence risk, an estimated one million UK residents are prescribed long-term benzodiazepines.<sup>9</sup> The medical profession and pharmaceutical manufacturers have persistently and

wrongly assured the public that SSRI antidepressants do not cause drug dependency. To protect themselves and their non-dependency claims, the medical profession has long insisted on the use of the term “discontinuation” symptoms rather than “withdrawal” symptoms, thus airbrushing the dirty words, “drug withdrawal” out of the discourse, and consequently, out of public awareness.

For two decades, it has been clear to me as a practicing physician that SSRIs commonly cause withdrawal problems. Traditionally, medical practitioners have mistaken SSRI drug withdrawal problems as recurrence of depression. Based on published research, Scottish GP Des Spence – who has repeatedly expressed many valid concerns about SSRIs – has written: “And when patients try to stop, half of them experience withdrawal with agitation, insomnia, and mood swings which many construe as a return of their low mood. Patients struggle to stop medication due to these physical and psychological withdrawal symptoms, so isn’t this a type of dependence? Anecdotally, patients elect to continue antidepressants, and remain stuck in a loop for years. And how safe are antidepressants when taken for decades? Why is there no systemic attempt to review long-term antidepressant prescribing?”<sup>10</sup> Given the relentless rise in UK antidepressant prescribing rates year on year – a staggering 64.7 million antidepressant prescriptions in England alone in 2016<sup>11</sup> – the Petitions Committee might take note of Dr. Des Spence’s last sentence above.

**Prescribed drug dependence – a UK “public health disaster”.** Prescribed drug dependence was correctly described in the title of a 2016 *New Scientist* article as a UK “public health disaster”.<sup>12</sup>

**The medical profession’s minimising of prescribed drug dependence; out of self-interest rather than the public interest.** It is profoundly embarrassing to medical doctors that substances they enthusiastically prescribe – with assurances of non-dependency – not uncommonly cause drug dependency and withdrawal problems. At a human level, one can understand the medical profession’s reluctance to admit to themselves and the public that substances they prescribe could cause quite widespread drug dependence. This is now particularly the case regarding SSRI antidepressants, heralded as harmless wonder-drugs since their launch in the 1980s, the flagship of the medical profession’s current psychiatric armoury. At a professional and public health level however, such widespread medical denial and minimisation of these problems are clearly unacceptable.

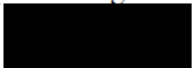
Because of the failure of the health system to recognise their prescribed drug dependency problem and provide anything approaching adequate support, thousands of people in the UK have turned to lay-created support groups. Over the years I have been contacted by many people in the UK, desperately seeking expert help and support in their efforts to come off prescribed benzodiazepines and SSRI antidepressants. I have been repeatedly struck by the lack of knowledge within the medical profession of how best to work with people seeking to withdraw from these substances. Protocols exist regarding withdrawal from benzodiazepines and SSRIs.<sup>13 14</sup> It appears that the majority of doctors do not adhere to the advice provided within these protocols. Many people who wish to come off these substances justifiably feel alone and unsupported in their efforts to do so. Many people have told me of their doctor’s unwillingness to engage seriously with them in a process of systematic drug withdrawal.

I respectfully caution your committee against acceptance of statements that might originate from medical sources that claim that prescribed drug dependence is not a significant public health issue, or that the medical profession has a handle on the problem. Neither is correct.

As the prescribers of these substances, the medical profession has “skin in the game” – the reputation of elements of the medical profession is at stake here. Therefore, their objectivity – conscious or otherwise – in such matters should not be assumed as a given.

Given the scale of the problem, in the public interest, there is an urgent need for (a) the extent of prescribed drug dependence – currently grossly underestimated and unaddressed – to be publicly identified and recognised; (b) the setting up of designated prescribed drug withdrawal centres, sufficient to meet the need. To my knowledge, there are few if any such drug withdrawal centres in the UK, a situation that is wholly inappropriate given the considerable public need.

On the whole, with a few exceptions, the medical profession – my profession – has for over half a century behaved dishonourably and irresponsibly in relation to prescribed drug dependence, prioritising self-interest over the public interest. This situation should not be allowed to continue.

  
Dr. Terry Lynch.

Keynote speaker, Samaritans Annual National Conference (Ireland), 21<sup>st</sup> March 2015.

Member, Expert Group on Mental Health Policy (*A Vision for Change*) 2003-6.  
Member, Independent Monitoring Group for *A Vision for Change* 2006-09.  
Member, Independent Monitoring Group for *A Vision for Change* 2009-12.  
Member, HSE Expert Advisory Group on Mental Health 2006-8.

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<sup>5</sup> Professor David Healy, *Mental Health Today*, April 2002.

<sup>6</sup> American Psychiatric Association Task Force on Benzodiazepine Dependency. Benzodiazepine Dependence, Toxicity, and Abuse. Washington DC: APA, 1990.

<sup>7</sup> “Where the goalposts of dependence used to be”, Charles Medawar, Social Audit UK.

<https://www.socialaudit.org.uk/350goalp.htm>

<sup>8</sup> World Health Organisation (1998), “Selective Serotonin re-uptake inhibitors and withdrawal reactions”, *WHO Drug Information*, 12, 3: 136-8.

<sup>9</sup> “Benzodiazepines revisited”, *British Journal of Medical Practitioners*, 2012

<http://www.bjmp.org/content/benzodiazepines-revisited>

<sup>10</sup> “Bad medicine: The rise and rise of antidepressants”, Dr. Des Spence, *British Journal of General Practice*, Br J Gen Pract 2016; 66 (652): 573.

[http://bjgp.org/content/66/652/573?utm\\_source=TrendMD&utm\\_medium=cpc&utm\\_campaign=Br\\_J\\_Gen\\_Pract\\_TrendMD\\_1#ref-10](http://bjgp.org/content/66/652/573?utm_source=TrendMD&utm_medium=cpc&utm_campaign=Br_J_Gen_Pract_TrendMD_1#ref-10)

<sup>11</sup> <https://www.theguardian.com/society/2017/jun/29/nhs-prescribed-record-number-of-antidepressants-last-year>

<sup>12</sup> “Addiction to prescription drugs is UK ‘public health disaster’”, *New Scientist*, 24 October 2016.

<https://www.newscientist.com/article/2110089-addiction-to-prescription-drugs-is-uk-public-health-disaster/>

<sup>13</sup> Benzodiazepine withdrawal protocol: <https://www.benzo.org.uk/manual/bzcha02.htm>

<sup>14</sup> SSRI antidepressants withdrawal protocol: <https://www.benzo.org.uk/healy.htm>



Noel Thomas MA MB ChB DCH DRCOG DTM&H MFHom

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED] 9.1.2018

David John Rowlands AM  
Chair – Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
CF99 1NA

Dear Mr Rowlands

re Prescription drug dependence and withdrawal - recognition and support.

I write to express my support for this petition, which I have already signed.

It will soon be fifty years since my medical graduation. Social Psychiatry and Therapeutic Communities were making huge differences to the way that psychiatric patients were treated at that time, and it was my very good fortune to work with Dr David Clark at Fulbourn Hospital, and Dr Maxwell Jones, at Dingleton Hospital. The concern shown by both men to avoid medication as much as possible, while understanding and optimising a person's milieu had a lasting effect on my approach to mental health.

For more than three decades after my return to join my father in general practice in Maesteg, in 1972, I worked with my partners in practice in an industrial valley, with high morbidity rates, high consultation rates, but without an appointment system. Our prescribing costs and use of anxiolytics and antidepressants were well below the average for Wales. Our practice population was very stable, we declined the very many people who wished to join the practice.

We tried to give people with complex problems more time, rather than more medication.

Since retirement from full time NHS work in 2005, I have continued to work as a part time GP locum.

I undertook Tropical Medicine training before retiring, and have worked, annually, for extended periods, in six developing countries.

I have had extensive experience in homeopathic practice, within the NHS, for 30 years.

My wife and I have provided a free weekly homeopathic clinic for asylum seekers, in Swansea, for five years.

I provide a weekly homeopathic session for Sandville Court self-care centre, near Porthcawl.

I see children who are referred with behaviour problems, ASD, ADHD etc.

I do no private practice, non-NHS patients may donate to African charities.

Because of the great variety of people who consult me, from many different backgrounds and practices, I have an insight into the prescribing habits of doctors over a wide area.

Many of the asylum seekers we see have been put on psychotropics when living temporarily in England.

As a full time GP I was uneasy about the level of psychotropic drug prescribing, in this area, that our LHB reports revealed.

I no longer see those reports, but I do see, regularly, in the above settings, examples of what appear to be over prescription of psychotropic drugs. This causes me huge concern. I also see many patients whose symptoms may, in large or small part, be due to the medications they are taking, for presumed mental health reasons. This applies, to a much lesser extent, to patients on analgesic medication.

It has always proved extremely difficult to enable people to reduce and stop medication that may be doing them more harm than good.

I have great sympathy for doctors in primary care, with busy short appointments. This system encourages quick fix prescriptions in complex cases. Very often this makes for increasing problems in future months and years.

Regardless of any sympathy I might feel, these apparent over-prescribing responses are the makings of a disaster.

This is not an original opinion of mine.

Dr David Healy's books have made the situation very clear., for many years.

Peter Gøtzsche, in "Deadly Pschiatry and Organised Denial" has detailed the enormous harm that results from psychotropic drugs.

No surgeon should operate on a part of the body without knowing it's anatomy, and no one should be allowed to prescribe psychotropic drugs without reading his book.

It is a comment on the enormous power of the pharmaceutical industry, that it can manipulate and suppress informed debate on this subject, so that a petition like this has to be made to the Welsh Assembly, to draw attention to a problem that creates misery, ill health, and deaths, on a huge scale.

We desperately need greater awareness of the extent of prescribed drug dependence, a determination to reduce it, and to offer help to those who suffer from it.

Yours sincerely

Noel Thomas

A black rectangular redaction box covering the signature area.

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

David John Rowlands AM  
Chair - Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
CF99 1NA

17 January 2018

Dear David

**Petition: Prescription drug dependence and withdrawal - recognition and support (number 1235)**

My name is James Moore, I live in Monmouthshire and I am writing in support of the e-Petition: Prescription drug dependence and withdrawal - recognition and support.

I am currently in the midst of an extremely unpleasant and distressing attempt to withdraw from antidepressant drugs. I am one of the many people who experience profound and debilitating effects when they stop taking their psychotropic medications after a prolonged period of use (up to 63% of those taking antidepressants according to the Royal College of Psychiatrists). In a recent trial undertaken in the Netherlands, only 6% of long term users who wished to stop their antidepressant drugs were able to do so. Unfortunately, in my experience, medical knowledge of this and the experience required to support someone who is struggling is extremely difficult to find. In my case, the severity of withdrawal has cost me my career after 20 years in the UK Civil Service. I am now unemployed and barely able to function at all, I am a burden to my family and to society, all because of taking a psychiatric drug that I was told would 'help me'.

There are many problems inherent in the liberal prescribing of psychiatric prescription drugs but they can be summarised as:

- Doctors often do not tell patients when they start psychiatric drugs that there may be issues with dependence and withdrawal at the end of treatment.
- Doctors seem quite content to leave patients on these drugs for far longer than is necessary or even helpful, medication reviews are few and far between.
- Many patients are prescribed one psychiatric drug after another, so they end up on a cocktail of medications, making adverse effects more likely and withdrawal more difficult.

- The NICE guidelines that doctors use to try and support those who wish to stop their medications are wholly inadequate and not based on any sound science or evidence, indeed it is actually impossible for patients or doctors to comply with the guidelines as they are written.
- Doctors cannot rely on the pharmaceutical manufacturers for advice or guidance, as they don't acknowledge that there are any problems with withdrawal even though their own clinical trials clearly demonstrated that dependence occurs after a short period of taking the drugs.
- The evidence tells us that the dramatic increase in prescriptions for psychiatric drugs are because more patients are becoming dependent and unable to stop, rather than new prescriptions.
- Many prescriptions for antidepressant, antipsychotic or anxiolytic drugs are not for their indicated psychiatric conditions, but for 'off-label' uses such as insomnia, chronic pain or migraines, there is little evidence that these drugs are effective for these other uses and those taking the drugs for a variety of non-psychiatric conditions are never told of the dependence potential.

The result of this is that we are prescribing millions of drugs with a high dependence potential with scarcely a thought as to how we may manage the process of getting people off their drugs safely and with the minimum cost to our economy and to the long-term health and well-being of patients.

There is an alarming gap in services for dependent patients and this needs addressing urgently. If I were dependant on alcohol or nicotine, there would be a range of support services that I could access, both within the public and the private sectors and many that are partly funded by the alcohol or tobacco industry. Why should the users of prescribed drugs be left with no advice or support?

We have the opportunity, through a helpline and formal guidelines for prescribers, to address this issue, help patients and better support doctors too. I fully support this petition and call on the Welsh Assembly Government to back our request for recognition of this problem and specific support for those of us who have followed our doctor's advice to the detriment of our health and at significant personal cost to ourselves and our families.

Yours sincerely

James Moore

Email: [REDACTED]

Mobile: [REDACTED]

Web: [www.ifmoore.co.uk](http://www.ifmoore.co.uk)

# Agenda Item 3.8

## **P-05-790 Tackle Rough Sleeping**

This petition was submitted by Hanin Abou Salem having collected 71 signatures online.

### **Petition Text**

We're calling on the Welsh Government to tackle rough sleeping in Wales. A devolved government is a "government closer to the people," all the people! I recently moved to Wales and I have fallen in love with everything Welsh. But every day my happiness is mixed with immense sadness because I pass so many people sleeping rough in the streets. Their ongoing misery is an affront to my humanity. As an individual I cannot solve their problem on my own but together as a government and people we can make a difference. The homeless people I pass every day in Wales have indicated that they feel like "forgotten people". They live in a vicious circle which can only be broken if the government sets a clear strategy to get them off the street and into a safe accommodation so they regain their lives. About 2 weeks ago I passed a homeless person and someone commented that individuals sleeping rough want to be homeless. As I was arguing against this logic we passed a homeless man near city road reading a book!

No one chooses to be homeless. People become homeless as a result of certain circumstances and the government has a duty to get people off the street so they can be active citizens who can live with dignity, have access to work opportunities and be able to vote. The Housing Act (Wales) 2014 required all councils in Wales to help anyone at risk of becoming homeless within 56 days does not solve the problem of individuals who are already homeless and sleeping in the streets. We need to address rough sleeping now!

### **Assembly Constituency and Region**

- Cardiff Central
- South Wales Central

Rebecca Evans AC/AM  
Y Gweinidog Tai ac Adfywio  
Minister for Housing and Regeneration



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref P-05-790  
Ein cyf/Our ref RE/05161/17

David John Rowlands AM  
Chair - Petitions committee.  
National Assembly for Wales  
Cardiff Bay  
CF99 1NA

government.committee.business@wales.gsi.gov.uk

9 January 2018

Dear David,

Thank you for your letter of 12 December regarding petition P-05-790 Tackle Rough Sleeping. The petitioner has suggested a number of possible actions which they believe are needed to address the apparent increase in rough sleeping.

We believe that no person should need to sleep rough. Recent increases in rough sleeping are a concern for both myself and for my Government colleagues, and addressing this issue is a priority. The causes of rough sleeping involve personal and structural factors, which often interact. Employment and welfare benefit problems can make the context very difficult for people on low incomes. These issues are often compounded by personal problems such as ill health, substance misuse and criminal behaviour.

Outreach and other services for rough sleepers have increased over recent years, but access to emergency accommodation remains inconsistent. My officials are working with partners in local authorities and the voluntary sector to target areas where there are shortages of services. The draft budget highlights our commitment to tackle this issue. We know that some rough sleepers become entrenched in sleeping rough, and may become unwilling to try better alternatives for a number of complex reasons.

Bae Caerdydd • Cardiff Bay  
Caerdydd • Cardiff  
CF99 1NA

Canolfan Cyswllt Cyntaf / First Point of Contact Centre:  
0300 0604400

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[Gohebiaeth.Rebecca.Evans@llyw.cymru](mailto:Gohebiaeth.Rebecca.Evans@llyw.cymru)

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

We agree there is a need for better monitoring data and have funded the Wallich to develop a national continuous monitoring system. We are also funding a rough sleeper network co-ordinator post to design and roll out the new system and share best practice across Wales. This new system will provide quantitative data and information regarding a person's use of services over time.

I also agree that services should be tailored to meet individual's needs, and this can only be achieved by listening and understanding an individual's experience and future aspirations. Research being undertaken by Shelter Cymru to understand the reasons why people are finding themselves with no accommodation is supported by Welsh Government. The primary objective of the project is to learn about the experiences of people on the streets and their opinions of what would have prevented their homelessness. This research is being carried out in Wrexham, Cardiff and Swansea. I expect to receive the findings of this research in April 2018.

The petitioner has proposed a 'no rough sleeping policy'. Our policy position is that no one should need to sleep rough. I support the petitioner's suggestion on long term accommodation. The Welsh Government is supporting 'Housing First' projects across a number of areas, including Cardiff, which will help rough sleepers move into settled accommodation and ensure support is available to help them maintain their tenancy. We will monitor closely the progress and impact of these projects.

I do not support the assertion that our legal reforms are not helping homeless people in general. The duties owed to an individual within the Housing Act (Wales) 2014, for homeless people and those threatened with homelessness are consistent. Local Authorities must take reasonable steps to help to prevent homelessness and to secure accommodation where needed. This enables most people to avoid homelessness and the need to sleep rough. However, I recognise that practice at a local level does vary, and may not meet the complex needs of many rough sleepers. The petitioner raises excellent points regarding austerity and welfare cuts. These areas are non-devolved. We recognise the shortage of affordable housing and we have committed to delivering 20,000 affordable homes over the Assembly term.

I am aware of concerns over conditions in some emergency accommodation. In the summer of 2017, the former Cabinet Secretary for Communities and Children announced an additional £2.6 million to tackle homelessness. This funding has been allocated to local authorities who are using it to fund a range of initiatives, including capital investment to improve the quality of emergency provision in Newport, Cardiff and Wrexham. As previously mentioned, we are also committing revenue funding to further develop Housing First style approaches to help rough sleepers into settled accommodation.

In addition to the work we are undertaking we are also planning for the future. Officials are working with partners to develop a national action plan to tackle rough sleeping which will address the issues raised by the petitioner. This action plan will be based on the recommendations of the Rough Sleepers Working Group. I expect this plan to be published during February and to outline developments taking us into January 2020. The Rough Sleeper Action plan will be forwarded on to the committee once finalised.

This information evidences our firm commitment to tackling rough sleeping.

Yours sincerely,

A handwritten signature in black ink that reads "Rebecca Evans." The signature is written in a cursive, flowing style.

**Rebecca Evans AC/AM**  
Y Gweinidog Tai ac Adfywio  
Minister for Housing and Regeneration



# Agenda Item 3.9

## P-05-778 Protect the Razor Clams on Llanfairfechan Beach

This petition was submitted by Vanessa L Dye, having collected 225 signatures online and 234 on paper – a total of 459 signatures.

### **Petition text:**

We call on the National Assembly for Wales to urge the Welsh Government to:

- commission a research study to ascertain the state of the health of the razor clam beds and their viability as a long term natural resource, and put in place a moratorium for fishing of razor clams until the research can report its findings;
- ratify a 'closed' season for the harvesting of razor clams aligned to the spawning season i.e. May to September;
- draw up regulations in addition to the minimum landing size of 10cm to include set quotas that individuals are allowed to take; and
- bring forward legislation and regulations to protect the razor clams on Llanfairfechan beach.

"The mass harvesting of razor clams on Llanfairfechan beach has been a matter of concern for many residents and conservationists for a number of years." (Ref: letter to Cabinet Secretary Lesley Griffiths AM from Janet Finch Saunders AM 28th July 2017.

Currently the only regulatory control on razor clams is that they must have a legal minimum landing size of 10cm, and there are checks relating to the control of clams ending in the food chain. Many residents are concerned about the apparent lack of procedures and/or regulations governing the taking of razor clams particularly in respect of designating a 'closed' season during spawning, quotas allowed, and the need for research evidence to be conducted on the razor clams to ascertain the impact on the local environment and ecosystem.

Since 2013 it has been noted by several sources that razor clams are being harvested in great numbers from Llanfairfechan beach. Evidence to support this claim has been documented on numerous occasions on social media. A recent request on the Llanfairfechan Noticeboard for any pictures or video footage of those gathering the razor clams clearly shows that there are large numbers of people involved in this activity. The gathering of the razor clams generally takes place after a high tide.

**Additional information:**

Just to provide some historic background about this issue. In 2013 the harvesting activity was brought to light by the Weekly News newspaper by Tom Davidson when it was noted that there was “A gang of more than 100 people harvesting huge amounts of razor clams.....” There were also concerns that illegal workers were being exploited and that the clams were being fished for commercial purposes. At the time, one resident said “they had seen similar scenes involving an increasing number of gatherers over the last few weeks. Residents are angry at the sheer number of harvesters with fears the local habitat could be damaged irreparably, with hundreds of clams taken off the beach regularly.” Whilst fears about the gatherers being used as part of modern slavery and the shellfish ending up in the food chain have been allayed by the ongoing efforts of the police and Food Standards Agency. The environmental consequences of this sustained and systematic removal of razor clams remains a major issue, which may impact on the other marine and bird life within the area, along with causing possible changes in the density of sand on the beach. There are some fears regarding the sand being unstable in places and people unfamiliar with the beach could easily get into difficulties e.g. some gatherers harvest the clams some distance away from the safety of the land. It has been quite disempowering and frustrating for ordinary citizens to watch the pillaging of an environmental resource and question why organisations who's remit is to protect the environment appear to be hamstrung because of the lack of appropriate procedures/laws. This is surprising given that Llanfairfechan beach is designated as a Special Scientific Interest (SSSI), Special Protection Area (SPA) and Special Area of Conservation (SAC). 2013. Surely there must be regulations within these bodies of knowledge to tap into as a source to protect this imbalance in such an ecosystem?

**Assembly Constituency and Region**

- Not provided

Lesley Griffiths AC/AM  
Ysgrifennydd y Cabinet dros Ynni, Cynllunio a Materion Gwledig  
Cabinet Secretary for Energy, Planning and Rural Affairs



Llywodraeth Cymru  
Welsh Government

Eich cyf/Your ref P-05-778  
Ein cyf/Our ref LG/05399/17

David John Rowlands AM  
Chair - Petitions committee.  
National Assembly for Wales  
Cardiff Bay  
Cardiff Bay  
CF99 1NA

government.committee.business@wales.gsi.gov.uk

9 January 2018

Dear David

Thank you for your letter of 8 December regarding P05-778, Protect the Razor Clams on Llanfairfechan Beach.

I can confirm that the fishery will remain closed until the results of the razor clam stock assessment have been considered. To this end, I have extended the closure of the fishery until 31 December 2018.

Regards  
Lesley

**Lesley Griffiths AC/AM**

Ysgrifennydd y Cabinet dros Ynni, Cynllunio a Materion Gwledig  
Cabinet Secretary for Energy, Planning and Rural Affairs

Bae Caerdydd • Cardiff Bay  
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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

Dear Petition Committee Members,

Thank you for the opportunity to comment on Cabinet Secretary for Energy, planning and rural affairs letter which indicates that the prohibition of fishing for razor clams on Llanfairfechan beach has been extended until December 2018, to allow time for the *assessment of razor clam stocks*. The key comments follow:

**1. Need for Signs displaying closure of razor clam beds**

The majority of comments from Llanfairfechan Noticeboard Facebook group have shown a very positive response to the closure date. However, there is some concern that this letter is currently only displayed on one of the waste bins on Llanfairfechan promenade and it is hoped that signs indicating the razor clam bed closure will be prominently displayed at the various access points to the beach to ensure all potential gatherers are aware that this bye law is in place.

**2. Need for Fisheries authorities to ensure there are no breaches of closure**

As has been raised previously, (see original notes supporting the petition), there are concerns that the relevant fishery authorities are in attendance on occasions when gathering of the razor clams takes place i.e. following high/spring tides etc. so that any violations can be stopped.

**3. Capitalise on the unique research opportunity to explore and report on the razor clam beds**

It was very evident at an open meeting held on 24<sup>th</sup> July 2017 by Janet Finch Saunders(AM) that there was a dearth of existing evidence; being offered by the experts present; about the types, extent and health of the razor beds. In addition, there appeared to be a lack of extant information about razor clams on the internet. Therefore the current closure of the razor clam beds for assessment signals an ideal and unique opportunity to explore and gather findings of a virtually untrammelled area of research. Thus providing a great opportunity for any 'would be', or expert marine biologists, to provide kudos for the individuals involved. I.e. in terms of

published papers and conferences etc., along with a fulfilling a huge gap in benchmark evidence to inform 'fisheries' practices for the future.

I hope these comments are of use to the ongoing progress and discussion of the Petition Committee.

Yours sincerely,

Vanessa L Dye(Mrs)

-----

**Petitioner to Committee, 16.01.18**

Dear Kayleigh,

Thank you once again for this information. Along with attachment I sent you earlier I have one additional point to put forward to the Petition Committee. There have been a few comments on facebook (Llanfairfechan) saying that residents think the density of the sand in places seems improved since the closure of the razor beds has been in place.

Once again, thank you for your ongoing help

Kind regards

Vanessa

# Agenda Item 4

## **P-05-751 Recognition of Parental Alienation**

This petition was submitted by Families Need Fathers Both Parents Matter Cymru having collected 2,058 signatures – 752 on paper and 1,306 online.

### **Text of the Petition**

We call upon the Welsh Assembly to persuade the Welsh Government to protect children and young people in Wales by formally recognising 'Parental Alienation' as a form of emotional abuse of children. We further call upon the Welsh Government to take specific actions to reduce the impact of Parental Alienation on children and their families.

### **Additional Information**

We propose the following action by Welsh Government

- Recognise 'Parental Alienation' as emotional abuse of children with a definition incorporating the one given by the Ministry of Justice (paragraph 1) here <https://petition.parliament.uk/petitions/164983> )
- Commission and fund mandatory training for professionals including but not Social Work and Cafcass Cymru staff, in recognising Parental Alienation including pathways to protect children from harm.
- Establish and fund a national campaign to inform children and families about Parental Alienation and the harm that it causes.
- Place a duty on Welsh Ministers to act to protect children from abuse and harm where Parental Alienation has been identified.

Parental Alienation has been defined by the Ministry of Justice as:

‘In cases where parents are separated, parental alienation refers to a situation in which one parent (usually the parent with whom the child lives) behaves in a way which creates anxiety in the child, so that it appears the child is opposed to living or spending time with the other parent.’

This definition is taken from the first paragraph of the Government's response to Mr. Darren Towill's petition. <https://petition.parliament.uk/petitions/164983>

CAFCASS in England have already recognised Parental Alienation as an abuse of children. CAFCASS CEO Anthony Douglas stated in an article in the Telegraph online dated 12th Feb 2017 about Parental Alienation that "It's undoubtedly a form of neglect or child abuse in terms of the impact it can have".

<http://www.telegraph.co.uk/news/2017/02/12/divorced-parents-pit-children-against-former-partners-guilty/>

**Assembly Constituency and Region.**

- West Cardiff
- South Wales Central

Evidence for the Senedd Petitions Committee  
in respect of Petition P-05-751 *Recognition of  
Parental Alienation*

Prepared by: Dr Sue Whitcombe  
Chartered Psychologist, AFBPsS  
HCPC Registered Counselling Psychologist

Email: sue@suewhitcombe.co.uk

Date: 10<sup>th</sup> January 2018 (revised 17/01/2018)



1. I am a HCPC registered counselling psychologist, chartered with the British Psychological Society (BPS). I founded a social enterprise, Family Psychology Solutions CIC, with support from Teesside University to develop provision around parental alienation resulting from my research and doctoral training. I provide therapeutic interventions, offer consultancy and training, and have conducted research into parental alienation. I facilitate BPS approved training (CPD) on parental alienation for practitioners and professionals. I have been instructed to provide expert assessment and opinion in family law cases in England, Scotland and Wales. I sit on the Expert Witness Advisory Group of the BPS, am Chair Elect of the BPS Division of Counselling Psychology Welsh Branch and Chair of the BPS Training Committee in Counselling Psychology.
2. I support and volunteer on a pro bono basis for a number of charities who work with and for children and families. Families Need Fathers Both Parents Matter Cymru is one of these charities.
3. This petition calls for:
  - a. the recognition of parental alienation as a form of emotional abuse by the Welsh Government
  - b. mandatory training for professionals, including social workers and Cafcass Cymru staff, in the recognition of parental alienation and pathways to protect children from harm
  - c. a national campaign to raise awareness of the harm caused by parental alienation
  - d. a duty on Welsh Ministers to protect children from abuse and harm where parental alienation has been identified.
4. Parental alienation is characterised by a child's strong alignment, or enmeshment, with one parent whilst rejecting a relationship with the other, or presenting with an almost phobic fear of that parent. This rejection, or fear, seems unwarranted based on the entirety of the child's actual experience of that parent. As a condition which may be a focus of clinical attention, parental alienation is most readily categorised as a Parent-child Relational Problem (V61.20) or Child Affected by Parental Relationship Distress (V61.29). In some cases the behaviours of a caregiver in perpetuating an alienated condition in a child may be defined as Child Psychological Abuse (995.51) (American Psychiatric Association, 2013).
5. Many children impacted by alienation appear, on the surface, to function well. They may be seen as model pupils at school, polite and well-behaved. In my experience, school staff are shocked when they witness the out of character vehement rejection and callous response of a child when referring to a parent. However, studies have identified increased emotional and behavioural problems in alienated children as well as risks to a child's psychological and emotional development. Going into adulthood, those who have been alienated are more likely to have an impaired ability to sustain effective, healthy relationships throughout their life-course, including work and social relationships. In addition there is increased risk of mental health and psychiatric disorders, including disturbances in identity and personality functioning, and substance misuse.

6. The symptomatic behaviours and the underlying psychological processes in an alienated child have been independently identified since the 1980s by researchers and practitioners in social work, law and psychology. These behaviours include:
  - a. Psychological splitting, a lack of ambivalence, where a child idealises one parent and devalues the other. The child sees one parent as all good, the other as all bad. This is most readily apparent in the enmeshed relationship with, or reflexive support of, one parent. This polarised thinking often extends to the rejection of one side of the child's family in its entirety.
  - b. Apparent fear, irrational anxiety, refusal or resistance to being with a parent, or parenting time which is characterised by extreme withdrawal, gross hatred and animosity
  - c. An evident absence of guilt over poor behaviour towards the parent
7. These behaviours are the presenting features of a maladaptive coping strategy. Within the dynamics of a family system under stress, the child feels a loyalty conflict, is unwittingly co-opted into an unhealthy cross-generational coalition with one parent, or empowered or elevated to the role of decision maker in perverse triangulation, parentification or adultification processes.
8. Within this dysfunctional system, a child's critical thinking is impaired, they experience a cognitive dissonance – they are unable to reconcile their actual experience of a loved parent with the contrasting overt and implicit information received from the other loving parent.
9. In order to achieve some equilibrium, the child is driven (usually unconsciously) to reduce this psychological distress by rejecting the least vulnerable or least fearsome parent. This rejection enables a child to present, on the surface, as coping and functioning well.
10. A child is biologically and psychologically wired to connect with their primary caregivers in order to have their needs for sustenance, safety and security are met, enhancing the chance of survival. A child's attachment to their parent is innate, even when care is less than good. In general, children crave a relationship with their parent, even if their experience of that parent is poor and they have been subject to physical or sexual abuse or neglect.
11. Rejection of a parent is rare in a child, particularly in pre-adolescence, and is a key indicator that alienation may be present. Rejection or expressed fear in an alienated child is usually accompanied by a lack of evident emotion, or extreme displays of emotion which are disproportionate to their actual experience of the parent.
12. Psychological splitting – the idealisation of one parent and/or one side of the family and devaluing or rejection of the other parents and/or side of the family - is another key indicator of alienation.
13. In response to the petition, the former Cabinet Secretary for Communities and Children stated that the Family Justice Network:
  - a. Recognised that some parents can behave in a way that alienates the other parent from their child's life

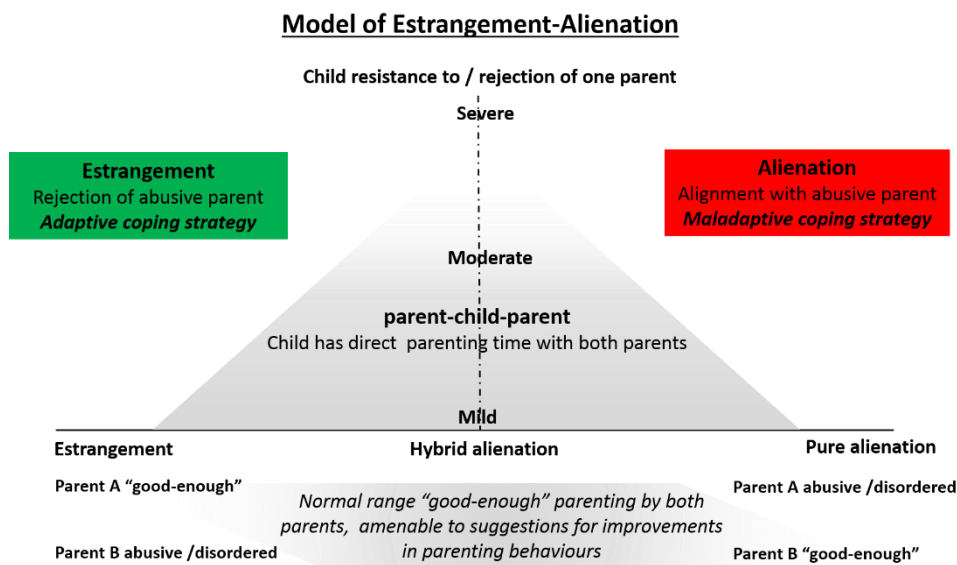
- b. Acknowledged the significant impact this type of behaviour can have on the emotional well-being of the child
  - c. Stated their belief that the Family Court already has sufficient range of powers to deal with cases where alienating behaviours feature
  - d. Acknowledged that some cases can and have been considered by Welsh local authorities under child protection procedures
  - e. Affirmed that parental alienation should continue to be dealt with using current legal provisions.
14. In his response, Mr Sargeant also stated that “CAFCASS Cymru practitioners, as professionally qualified social workers, are trained to understand and recognise the potential for implacable hostility by a party in divorce or separation cases and its potential impact on the child.” My professional experience suggests otherwise.
15. Having worked in academia and having close working relationships with academic social work professionals, my understanding is that parental alienation is not a core aspect of all Social Work curricula. In fact, my understanding is that it is not included in the majority of Social Work curricula at either undergraduate or postgraduate level. As such, the assertion that Cafcass Cymru practitioners, by virtue of the fact that they are qualified social workers, have sufficient understanding regarding parental alienation is likely to be incorrect.
16. Given that Sir Anthony Douglas, CEO of Cafcass, confirmed in October 2017 that it will likely take a considerable period of time before all Cafcass Family Court Advisers have a good understanding of parental alienation, it is clear that on recruitment to Cafcass, social workers are not required to have an understanding of parental alienation. To clarify, it is unlikely that their initial training included knowledge and skills around parental alienation, and certainly this would not have been universal.
17. As Cafcass Cymru draw from the same pool of social workers, albeit regulation of Social Work in Wales is by Social Care Wales and not the Health and Care Professions Council, it is unlikely that Cafcass Cymru practitioners, as professionally qualified social workers, **are** universally trained to understand and recognise parental alienation as was suggested by the former Cabinet Secretary for Communities and Children.
18. Social Care Wales’ (2013) *Evidence Matters in Family Justice Tools* resource pack for child and family social workers in Wales does not include parental alienation in the list of 57 areas of expertise in which social workers might be expected to have even a minimal knowledge.
19. Since 2014, I have delivered fourteen workshops on parental alienation to a total of 397 practitioners and professionals – practitioner psychologists, social workers, psychiatrists, family workers, mental health practitioners, counsellors, family therapists and trainees in these core professions. Data suggests that professionals across these disciplines have minimal knowledge of parental alienation prior to this professional development training.

<b>Parental Alienation Workshops – April 2014 – December 2017</b>			
Number of Workshops = 14 Number of Attendees = 397			
	<b>Scale 1-10 (1= very poor; 10=excellent)</b>		
	<b>Mean</b>	<b>Mode</b>	<b>Range</b>
Pre Workshop: <i>Please rate your knowledge or understanding of parental alienation</i>	3.49	3	1-8
Post Workshop: <i>Please rate your knowledge or understanding of parental alienation</i>	7.72	8	5-10
	<b>Scale 0-5 (1=not at all; 5=very useful)</b>		
<i>How useful will this training be in your client work?</i>	3.94	4	2-5
All feedback is provided anonymously			

20. All workshop delegates in clinical practice acknowledged more than one client on their caseload from the previous six months, in which parental alienation had likely been a factor.
21. Delegates expressed ongoing concerns following training that the lack of understanding of practitioners in Local Authorities would render it difficult for their concerns regarding a child to be dealt with appropriately should they wish to make a referral.
22. In November 2017, two employees of Cafcass Cymru, including one of the Heads of Operation, attended BPS Approved training in parental alienation facilitated by myself. These delegates reported that they believed they were able to identify cases where alienation is a factor though they would like to be able to identify these at an earlier stage. They reported that they were not always aware of the most appropriate intervention or where to access necessary interventions.
23. One delegate stated her belief that there were a very small number of these cases, though they made exceptional demands on resources. Establishing the prevalence of parental alienation is hampered by issues of data samples and definitions. In Wales, Cafcass Cymru have to date not seemed to be prepared to identify a case as one including alienation. Case management information does not appear to include this data. The most recent study of 610 randomly selected adults in the USA suggests that 13.4 percent of parents have been alienated from one or more of their children which is much higher than previous estimates (Harman, Leder-Elder, & Biringen, 2016).
24. In my experience, throughout the country and in Wales, recognition of cases where alienation may be a factor is inconsistent, and there are likely many more cases than are currently identified. In informal conversations with Family Court Advisors, Guardians and Local Authority Social Workers in Wales they have suggested an increasing number of cases

where alienation is likely present, a lack of knowledge and training in how to work with these cases and limited resources.

25. Parental alienation exists on a continuum from mild to severe. In reality, cases of family breakdown can be complex, often with co-existent intimate partner or domestic violence, substance misuse, long standing mental health issues, prior safeguarding and child protection issues. When faced with a child presenting as resistant to seeing a parent, vehemently rejecting a parent or displaying extreme anxiety or fear of a parent, it is important to determine whether this presentation is 'reasonable' or not, based on the entirety of that child's experience of that parent. Often, in my experience, there is a failure to unravel the complexity in cases.
26. Front-line practitioners in the UK are well-versed at evaluating families where there is recognisable abuse or poor parenting – the far left of the Estrangement-Alienation model. It is likely that both Parental Estrangement and Parental Alienation will be classified in the 11th revision of the International Classification of Diseases (ICD-11) due for issue in 2018. Established assessment, evaluation and intervention models used in typical cases of abuse and less than good parenting are core components of social work training.



27. A limited understanding of alienation often leads to a presumption that a child's resistance or fear is justified – 'there's no smoke without fire.' Incorrect assessment, formulation and intervention can be damaging, exacerbating alienation and on occasions leaving a child in the care of a psychologically abusive or psychologically unwell parent. My direct clinical and legal experience suggests that few practitioners are aware of appropriate interventions and their actions, or failure to act appropriately, in some cases likely exacerbates the emotional harm and psychological distress experienced by children.

28. In October 2016 I was commissioned to write an article by the editor of *Seen and Heard* for their readership of independent social workers, children's guardians and child protection social workers. The scope was to include the information needed to distinguish the

(potentially) alienated child from a child with other issues; approaches likely to be successful when trying to re-establish a relationship with a parent; approaches which have the potential to further damage the child; the pros and cons of a change of residence. For reference and clarification, the article which was published in 2017 and includes a comprehensive bibliography can be accessed here:

[https://www.academia.edu/35180977/Parental\\_alienation\\_or\\_justifiable\\_estrangement\\_Assessing\\_a\\_child\\_s\\_resistance\\_to\\_a\\_parent\\_in\\_the\\_UK](https://www.academia.edu/35180977/Parental_alienation_or_justifiable_estrangement_Assessing_a_child_s_resistance_to_a_parent_in_the_UK)

29. I have been instructed on cases in Wales where early indicators of alienation were not identified or acted upon leading to entrenched alienation, significant harm and psychological distress in the child.
30. There is a tendency, in my opinion, for many Cafcass and Cafcass Cymru practitioners to conceptualise cases as high conflict and a propensity to conflate 'high conflict' with alienation. Acrimony and conflict is often present in cases where there is parental alienation. However, the conflict is often a symptom of the alienation dynamic and the adversarial legal process; it is not a cause of the relationship breakdown or disagreement regarding child arrangements.
31. My clinical and legal experience in Wales suggests:
  - a. there are some excellent, knowledgeable Guardians who recognise parental alienation in its complexity and take appropriate action in seeking psychological assessments and involving the Local Authority
  - b. there are front line professionals in Cafcass Cymru who do not recognise the common signs of alienation, misinterpret and wrongly attribute a child's response, do not identify emotional harm, fail to suggest appropriate interventions and consequently prolong, and exacerbate, psychological distress and emotional harm.
  - c. Local Authority social workers rarely have an understanding of parental alienation and find those cases referred with concern around significant harm or child protection difficult to assess and manage appropriately.
  - f. despite the range of powers available to the Family Court, the limited knowledge and understanding on the part of practitioners results in a failure to ensure that it has the necessary information to make informed judgements in cases where alienation may be a factor.
32. In 2014 I completed my doctoral research into the experience of alienated parents. Whilst not the main focus of the research, the findings identified concerns for child welfare, mental health and safety and variable, often negative, experiences in relation to family proceedings and social care services. A report which detailed these findings was distributed to Local Family Justice Boards in England and Wales in 2015. A copy of this report is available here: [https://www.academia.edu/35475673/Whitcombe\\_2015\\_Summary\\_Report](https://www.academia.edu/35475673/Whitcombe_2015_Summary_Report)
33. To summarise, in my professional opinion, based on my clinical, training, research and family proceedings experience:

- a. The Welsh Government does not recognise parental alienation as a form of emotional abuse.
- b. There is minimal training of professionals, including social workers and Cafcass Cymru staff, in the recognition of the complexity of parental alienation and pathways to protect children from harm. There is no mandatory training.
- c. There is limited awareness of the harm caused by parental alienation.
- d. Current procedures and practices fail to protect children from psychological distress, abuse and harm where parental alienation is a factor.

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