THE WELST SLEED ADNOED SOCIETY 'Etase Who Sleep Win'



2 Greenfield Close Pontnewydd Cwmbran NP44 1BY www.welshsas.org

Mr G D Thomas Committee Support Officer Retitions Committee National Assembly for Wales

08/09/08

PETITION: SLEEP APNOEA P-03-156

Dear Mr Thomas

09 SEP 2008

would refer to your letter of 21/8 concerning the above petition. I trust the following information will prove useful to the Committee.

MEDICAL: Approva" is all Greek word meaning 'without breath'. In around 7% of the population during sleep the throat muscles become flaccid, collapse and block the airway. The patient's brain receives a message to this effect and wakens typically with a loud snort. This episode' can occur around 300 times a night but has been measured at around 1000 such episodes. The outcome is lethargy, constant headaches, lack of concentration, loss of libido and constantly falling asleep. This can and often does occur during driving and has led to catastrophic effects. While not suffering from Apnoea the person involved in the Selby rail disaster was suffering from sleep depravation. It has been medically shown that all the major organs in the body can not replenish themselves when deprived of oxygen during sleep. Therefore untreated Apnoea has led to heart disease, strokes, diabetes and kidney failure.

TREATMENT: Treatment for Apnoea is by means of a Constant Positive Airway Pressure (CPAP) machine. This blows air through a mask enabling the airway to remain open, thus resulting in the correct type of sleep. This machine has been recommended by NICE as being the best treatment for 'mild and severe' sleep apnoea. The machine costs from around £300 to £700 depending on specification.

(Continued)

THE SOCIETY: The Welsh Sleep Apnoea Society (WelshSAS) was formed around eight years ago to 'promote the understanding of breathing and sleep disorders'. There are around seventy paid members from four clinics in South Wales, Bristol, Swansea and Wrexham. The Society has provided equipment in the form of a bed for the Sleep Laboratory at the Royal Gwent and several diagnostic and treatment tools for the RGH and Nevill Hall. We operate a website (www.welshsas.org) and a 'helpline' facility for patients and their families. Members receive a magazine twice yearly.

INVOLVEMENT WITH THE NATIONAL ASSEMBLY: The Society became aware that an unnamed patient had written to Edwina Hart concerning a CPAP. It seems the gentleman had been informed he couldn't get one on the NHS and had purchased a machine privately. He has written to the Minister requesting a refund of his money. Since a NICE Technology Appraisal earlier this year there has been a legal requirement on the Government and Local Health Boards to provide CPAPs to diagnosed patients. In a letter to the patient the Minister stated that she hoped that 'all diagnosed patients would have access to CPAP by June (which June wasn't stated). The Society has contacted the Minister concerning this matter and her insistence that Local Health Boards should be funding the equipment despite being te-organised. Until the Society has proof from a patient that they have been unable to obtain a CPAP we are at an impasse with the Minister. The Society then received an email from a couple in Cardiff who had been told that 'diagnosis and treatment of Apnoea was not available on the NHS in Wales'. Knowing that this is not true the Society has contacted the Minister again asking why there is a "Post Code Lottery' for treatment of Sleep Disorders. To date there has been no reply. Copies of the letters have been sent to Nick Ramsay AM and Jonathon Morgan AM as both have expressed an interest in developments. The Society is aware that services for patients with sleep disorders are at best fragmented and at worse non existent.

In the Society's view the Government are 'playing with patient's lives' here. A disorder that can be easily treated, allows patients to return to work, and improves their family life is being completely ignored. Yet an untreated patient with apnoea can kill an innocent bystander and themselves by falling asleep while driving.

I have enclosed copies of correspondence received from the Minister and Nick Ramsay.

I hope this information proves useful to the Committee. If they or anyone else wishes to contact me they should do so either through the website or on 01633 774087.

Yours sincerely

(Honorary Secretary)

Nick Ramsay AM

Welsh Conservative Member for Monmouth Shadow Minister for Local Government and Public Services

> Cardiff Bay, Cardiff, CF99 1NA Bae Caerdydd, Caerdydd, CF99 1NA

Eich cyf / Your ref:
Ein cyf / Our ref: ELW/NR/PR1 Ffôn/Tel: 029 20 898337
September 2008 Nicholas Ramsay@wales.gov.uk

Mr Roger Paterson,
Hongrary Secretary – the Welsh Sleep Apnoea Society,
2 Greenfield Close,
Pontnewydd,
Cwmbran,
NP44 1BY.

Many thanks for your letter of 18th August 2003.

Har A Patison

Tappreciated the information provided. As you know I am interested in being kept updated on the responses you receive from the Welsh Assembly Health Minister.

I was concerned to hear about the gentleman from Cardiff who has been informed that treatment for the diagnosis of sleep disorders is no longer available on the NHS. As we are both aware through our correspondence with Edwina Hart, all patients diagnosed with Obstructive Sleep Apnoea (OSA) should have access to Constant Positive Airway Pressure machines (CPAP). The fact that there are issues over equity of access in parts of Wales is an issue that needs to be addressed.

I would be grateful if you could send me some further information on your AGM on 11th October. Diary permitting, I would hope to attend, so if you could let me know the time and location of the meeting I would really appreciate it.

Kind regards,

Nick Ramsay AM

Welsh Conservative Member for the Monmouth constituency Shadow Minister for Local Government and Public Services

Nick Ramsay AM

Welsh Conservative Member for Monmouth
Shadow Minister for Local Government
and Public Services

Cardiff Bay, Cardiff, CF99 1NA Bae Caerdydd, Caerdydd, CF99 1NA

Eich cyf / Your ref: Ein cyf / Our ref: ELW/NR/PR1 August 2008

De A. Pokno

Ffôn/Tel: 029 20 898337 Nicholas.Ramsay@wales.gov.uk

MrRoger Paterson, Honorary Secretary – the Welsh Sleep Apnoea Society, 2 Greenfield Close, Pontnewydd, Cwmbran, NP44 1BY.

Fam writing to thank you for your most recent letter, received on 6th August 2008.

It is a concern that although the Health Minister, Edwina Hart AM, states that all patients diagnosed with Obstructive Sleep Apnoea (OSA) should have access to Constant Positive Aiway Pressure machines (CPAP), she admits that there are in fact issues over equity of access in parts of Wales.

As you know, Ms Hart has suggested that any patients who believe they are being disadvantaged should write to the Chief Executive of their Local Health Board. I do however understand your concerns over the potential impact of the reorganisation of the LHBs. I would be grateful if you would keep me updated on any response you receive from the Health Minister regarding this.

Lam more than happy to discuss this matter with my colleague, the Shadow Minister for Health, Jonathan Morgan AM, and have therefore copied him into our letters. I am sure that he would be as keen as I am to see that OSA patients are able to access CPAP machines.

Please feel free to contact me again if there is anything further you would like to discuss.

With kind regards,

Nick Ramsay AM

Welsh Conservative Member for the Monmouth constituency Shadow Minister for Local Government and Public Services

Compathan Morgan AM, Shadow Minister for Health and Social Services.

Edula Harr AMMBE

Mr Roger Paterson

Honorary Secretary

2 Greenfield Close

Y Swellinger dros techyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

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EH/03796/08

Your ref

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Deiri Du Patero.

The Welsh Sleep Apnoea Society

ി[®]August 2008

Cardiff CF99 1NA

Thank you for your further letter of 28 July about the provision of Continuous Positive Airway Pressure (CPAP) machines for patients suffering from sleep apnoea.

Lean assure you that the reorganisation of the NHS in Wales will not effect the high standards of care provided to patients. I can only repeat the advice in my earlier reply that you advise your members who have not received a CPAP machine in accordance with the NICE guidance on Sleep Apnoea to address their concerns to the chief executive of their Local Health Board, drawing their attention to the statutory obligation to fund implementation of the NICE guidance.

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Y Gweiniger dies ledayd a Gwasanaethau Cymdeithasol Minister for ffealth and Social Services

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EH/03150/08

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Roger Paterson
Honorary Secretary
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2 Green field Close
Pontnewydd
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Acces por Paterson

🍞 July 2008

Thank you for your letter of 23 June about the provision of CPAP machines for patients suffering from sleep apnoea.

I confirm my expectation that, in the light of the recent NICE technology appraisal, any patient prescribed a CPAP machine should receive one. I am, however, aware that there are issues over equity of access in parts of Wales.

May I suggest that you advise any members who believe they are being disadvantaged to write to the Chief Executive of their Local Health Board setting out their concerns, and asking that their case be investigated.

Auch.

Nick Ramsay AM

Welsh Conservative Member for Monmouth Shadow Minister for Local Government and Public Services

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Eich cyf / Your ref: Ein cyf / Our ref: ELW/NR/PR1

A. Phin

Mr Roger Paterson,
Honorary Secretary – the Welsh Sleep Apnoea Society,
2 Greenfield Close,
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NP44 1BY

I am writing to thank you for your letter regarding the recent NICE Technology Appraisal and the supply of CPCPs (Constant Positive Airway Pressure) to those diagnosed with OSA (Obstructive Steep Apnoea).

Lwas interested to read the Health Minister's statement that 'all patients diagnosed with OSA will have access to a CPAP by the end of June', as this would certainly be a welcome development.

However, it is a concern that the Sleep Clinic has no new money to provide for the twenty patients waiting – some as long as eight months. Furthermore, only two of the six Local health Boards who are responsible for allocating funding have contacted the Sleep Centre concerning the appraisal.

I have therefore contacted the Minister, as requested, to further raise this matter. I am interested to know what she is doing to ensure that patients with OSA do indeed have access to a ©PAP and I promise to contact you again as soon as I receive a response.

In the meantime please feel free to contact my office if there is anything further you would like to discuss.

Kind regards.

Nick Ramsay: AM

Welsh Conservative Member for the Monmouth constituency Shadow Minister for Local Government and Public Services

lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

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Our ref: EH/01983/08

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April 2008

Dais M. Lon

Thank you for your further letter dated 9 April about reimbursement of the costs o the Continuous Positive Airway Pressure (CPAP) machine you purchased privatel for sleep apnoea problems.

As I stated in my previous letter dated 25 February, I was sorry and disappointed to hear that you felt unable to rely on NHS Wales to provide you with a CPAI machine and opted to pay for one privately. There is no policy in Wales for the NHS to refund equipment or treatment purchased privately.

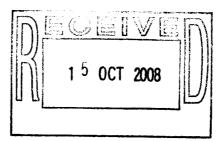
You ask about access to these machines now that NICE has formall recommended them as a possible treatment for adults with moderate or sever steep apnoea. LHBs are under a statutory obligation to fund implementation of thi guidance within three months. By the end of June, I would expect that all patient who have had CPAP machines prescribed would have been provided with them.

Edwina Hart AM MBE

Y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Our ref: EH/04485/08 Your ref: PET-03-156

Val Lloyd AM
Chair of the Petitions Committee
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14^mOctober 2008

Down Val

Thank you for your letter dated 12 September, on behalf of the Petitions Committee about a sleep disorders petition submitted by the Welsh Sleep Apnoea Society.

The National Institute for Health and Clinical Excellence (NICE) has issued technology appraisal guidance on the use of Continuous Positive Airway Pressure (CPAP) for the treatment of moderate or severe sleep apnoea, and has recommended its use, subject to certain criteria. Local Health Boards (LHBs) are under a statutory obligation to fund implementation of this guidance.

Further investment by the LHBs may be needed in local sleep apnoea services to achieve sustainable services that meet growing patient referrals. These longer term service developments will take time to implement but, in the meantime, LHBs will need to work with their partner NHS Trusts to agree how to address the number of patients who are waiting for sleep assessments and CPAP machines.

The Service Development and Commissioning Directives for Respiratory Conditions outlines the Welsh Assembly Government's policy for such conditions, including sleep disorders. It aims to ensure that the right services are provided in the right place, at the right time and by the right person, by refocusing resources to meet local needs, utilising multidisciplinary and multi-agency teams. These teams must become the bedrock in managing these conditions, including sleep disorders, in primary, secondary and social care. The directives reinforce the use of NICE technology appraisal as identified above and specifically identify key solutions and recommendations to address Obstructive Sleep Apnoea (OSA). These include improved universal diagnostic services for OSA in Wales, proactive programmes for

the management of the major risk factors of OSA including obesity and access to simple diagnostic facilities in acute admitting hospitals.

The implementation of the objectives outlined in the policy document is a local joint responsibility for LHBs and NHS Trusts. The Welsh Assembly Government is currently undertaking a review of progress to date. The findings of this review will be presented to me at the end of October and will be used to identify any follow-up actions that I consider need to be taken.

Mr.

Thomas, Gareth David (APS - Committee Services)

Dear Mr Thomas

Thanks for your letter of 21/11 concerning the above petition.

The Society would point out that the Minister states that 'It will take time to implement the NICE guidlines" but there is no urgency here. The Assembly Government and the LHBs have a statutory duty to implement the NICE guidlines within 6 months - from February 2008. The Minister has stated in writing that she expects all patients who needed a CPAP to 'have one by June' yet we know of 40 people waiting at the RGH Newport alone. The Service Development and Cpmmissioning Directives for Respiratory Conditions is little more than a 'talking shop' despite several meetings and a report absolutely nothing has been done and now there is a further delay while another report is commissioned. While all this is going on patients are suffering peolpe in the real worlsd are not getting the diagnosis and treatment they deserve they are driving and run the real risk of killing themselves and someone else for Christams.

The Minister advised a patient to request that his LHB refer him to the RGH for treatment - they refused - why? - because the LHB is being re-organised and they dont know what budget they will have or if they will have an OSA treatment outlet of their own. The Minister refuted in a letter to the Society taht LHBs would act in this way.

The Minister states that she wishes to be 'proactive' in providing improved diagnostic services - she has done absolutely nothing to improve the service and thuis is a disgrace.

Roger Paterson Honorary Secretary WelshSAS

Edwina Hart AM MBE

Y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Our ref:

EH/05433/08

Your ref:

PET-03-156

Val Lloyd AM Chair – Petitio

Chair – Petitions Committee National Assembly For Wales

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17 DEC 2008

S¹December 2008

Lew Val

Thank you for your letter of 24 November asking for an update on the Welsh Assembly Government's review of progress in the treatment of sleep apnoea, since my last letter to the Committee of 14 October.

Local Health Boards (LHBs) were required to report on progress against the actions specified in the Service Development and Commissioning Directives for Respiratory Conditions, which includes, but are not specific, to sleep apnoea services by the end of September . All LHBs returned a progress report and results indicate that all have made progress in taking forward the actions contained in the Directives. There is variation in progress across Wales on a number of key actions which we will be following up. In the development of care pathways for COPD, cystic fibrosis respiratory infections and sleep apnoea, over half had these in place, seven partially and the remaining were ongoing. The National Leadership and Innovation Agency for Healthcare (NLIAH) will be providing continued support to this work.

The Chronic Conditions Management Demonstrator in Carmarthen will also be helping to apply these Directives in practice. This will be shared with the rest of Wales and will help provide further impetus to support the actions and improvements that are outlined in the document.

As I confirmed in my previous letter it will take time to implement some of the service improvements required to achieve better and more sustainable services to meet growing patient referrals. In the interim LHBs must work with their NHS Trust to agree how to address the number of patients waiting for sleep assessment and treatment. Future reconfiguration plans should also help ensure that this is undertaken in a more integrated way.

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Edwina Hart AM MBE

Y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Our ref:

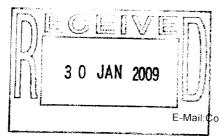
EH/00220/09

Your ref:

PET-03-156

Val Lloyd AM Chair **Petitions Committee** National Assembly for Wales Cardiff Bay

Cardiff **CF99 1NA**



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Lear Val

30 January 2009

Thank you for your further letter of 20 January asking for an update on progress with the Service Development and Commissioning Directives for Respiratory Conditions and specifically those actions relating to sleep apnoea.

The Directives provide an outline improvement of respiratory conditions generally. The implementation of the actions contained in the document are a local joint responsibility for Local Health Boards (LHBs) and NHS Trusts, performance managed by the Regional Offices. LHBs were required to report on progress against each of the actions contained within the Directives by the end of September 2008. All LHBs returned a progress report and results indicate that they have all made progress in taking forward the actions, although there is some variation in progress of these across Wales on a number of the key actions which we are following up.

In the development of care pathways for Chronic Obstructive Pulmonary Disease (COPD), cystic fibrosis respiratory infections and sleep apnoea, over half of LHB's had these in place, seven partially and the remaining were ongoing. We do not hold any figures centrally on the numbers of patients awaiting sleep assessment nor the length of wait for assessment. LHBs and Trusts have been tasked to work together however to address the numbers of patients awaiting sleep assessment and treatment. The National Leadership and Innovation Agency for Healthcare (NLIAH) will be continuing to provide support to this work.

Edwina Hart AM MBE

Y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Our ref:

EH/00943/09

Your ref:

Val Lloyd AM

Chair

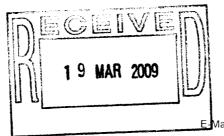
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18¹ March 2009

Day Val

Thank you for your further letter of 6 March about sleep apnoea services and its related petition.

As you will be aware from my previous letter, an audit was carried out in September 2008 of all Local Health Boards' progress in implementing the Respiratory Directives, including those for sleep apnoea. Results indicated a variation in progress across Wales and as a result we will be repeating this audit in September 2009. I will expect all LHBs to have care pathways in place for sleep apnoea and other respiratory conditions by this time.

I also explained that in the light of the NICE guidance published in March 2008, any patient prescribed a Continuous Positive Airway Pressure (CPAP) machine to assist their breathing should receive one. Patients however must be treated according to clinical need and it is a matter for clinicians to decide on appropriate treatment for their patients.

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GOZ

Edwina Hart MBE OStJ AM

Y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Our ref:

EH/07330/09

Your ref:

P-03-156

Val Lloyd AM
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§ December 2009

Dew Val

Thank you for your letter dated 26 November on behalf of the Petitions Committee about the implementation of the Respiratory Directives.

The National Leadership and Innovation Agency for Healthcare (NLIAH) has undertaken the 2nd annual audit of progress made by Local Health Boards (LHBs) against the key actions set out in the Service Development and Commissioning Directives for Chronic Respiratory Conditions. LHBs were required to submit responses to NLIAH by 30th September 2009.

NLIAH are currently finalising the report detailing the full audit results for the Chronic Respiratory Conditions Directives which will be issued next week. Preliminary results have shown that considerable progress has been made by the LHBs in meeting many of the key actions. The specific key action relating to care pathways for chronic respiratory conditions, including sleep apnoea, has shown that each of the seven integrated LHBs have developed care pathways but further development work is still required to fully comply with the action.

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Edwina Hart MBE OStJ AM

Y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Our ref:

EH/00325/10

Your ref:

P-03-156

Christine Chapman AM

Chair

Petitions Committee

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February 2010

Thank you for your letter dated 29 January on behalf of the Petitions Committee about sleep apnoea requesting details of the further development work required by Local Health Boards (LHBs) to fully comply with the Respiratory Directives.

The National Leadership and Innovation Agency for Healthcare (NLIAH) undertook the 2nd annual audit of LHBs progress against the key actions set out in the Directives in December 2009. The results show that considerable progress has been made in meeting many of the key actions since 2008 however further development work is still required by LHBs to achieve full compliance. NLIAH's audit report identifies the particular gaps that remain outstanding in each LHB area and I have written to LHBs requiring them to achieve full compliance with the Directives in time for the next audit in September 2010.

To assist LHBs in achieving this, a workshop is being held on March 30th, 2010 which will bring together all those involved in the planning and provision of respiratory care to identify and share best practice with each other and lessons for practical implementation.

en

Edwina Hart MBE OStJ AM

Y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Our ref:

EH/01152/10

Your ref:

P-03-156

Christine Chapman AM
Chair - Petitions Committee
National Assembly for Wales
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19 April 2010

Thank you for your letter dated 30 March on behalf of the Petitions Committee requesting details of the further development work required by Local Health Boards (LHBs) to fully comply with the Respiratory Directives.

The audit of the Directives for Chronic Respiratory Conditions undertaken by NLIAH has established that across Wales, 56% of all the key actions have been met and 40% of the actions have been partially achieved. The audit identified that good progress has been made across each domain however more work is required by each LHB to meet the key actions contained within the 'Diagnosis, Treatment and Management' domain.

The workshop held on 30 March 2010 was organised to help each LHB identify the specific actions required in each locality so that full compliance with the Directives is met in time for the next audit. Best practice and lessons for improvement were shared across organisations and a clear timetable for completion was communicated. Paul Williams, the Director General of Health and Social Care, is writing to each Chief Executive following the workshop to reinforce this message.

A workshop is also being held on 16 April 2010 to specifically look at the provision of ventilation services across Wales including sleep apnoea.

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Edwina Hart MBE OStJ AM

Y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Our ref:

EH/01687/10

Your ref:

P-03-156

Christine Chapman AM

Chair

Petitions Committee

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27 May 2010

Thank you for your letter of 18 May on behalf of the Petitions Committee about sleep apnoea services.

The Ventilation Workshop held on 16 April produced some clear actions to help improve treatment for those with sleep apnoea. Concern was raised by delegates regarding the diagnostic test for sleep apnoea not being included in the Referral to Treatment (RTT) 26 week wait target.

I have therefore asked my officials to raise this as a matter for consideration at future reviews of the RTT target to help ensure that unnecessary long waits for this procedure are not experienced.

In addition, I will also be writing to all Local Health Boards (LHB) to remind them of the NICE technology appraisal produced in March 2008 that recommended a range of clinically effective treatments for sleep apnoea. I will expect all LHBs to ensure that any patient that is prescribed a CPAP machine to assist their breathing should receive one.

Lu



Cyfarwyddiaeth Nyrsio Ffôn: 01874 712652 Ffacs: 01874 712554 **Nursing Directorate** Phone: 01874 712652 Fax: 01874 712554

e-bost/email:: carol.shillabeer@powyslhb.wales.nhs.uk

Our ref: CS/CP/FOI/10.R.080 14 June 2010

correspondence sent via email to: Christine.Chapman@wales.gov.uk Christine Chapman Chair, Petitions Committee National Assembly for Wales Cardiff Bay Cardiff. CF99 1NA

Dear Ms Chapman

Request under Freedom of Information Act 2000

Further to your previous correspondence in respect of your request for information which we originally received on 1 June 2010, I can confirm in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Health Board holds the information you asked for.

I am therefore pleased to enclose the information held by the Board. If you need any further assistance, please do not hesitate to contact us at the address below.

I trust this information is helpful to you. If you are dissatisfied, with the way your request has been dealt with by the teaching Health Board (tHB), you have the right to request a review in which case you should write to:

Andrew Cottom
Chief Executive
Powys Teaching Health Board
Mansion House
Bronllys
Powys
Brecon
LD3 OLS

Bwrdd Iechyd (addysgu) Powys Y Plasty, Bronllys, Aberhonddu, Powys LD3 0LS Ffon: 01874 711661 Ffacs: 01874 712554 Powys (teaching) Health Board Mansion House, Bronllys, Brecon, Powys LD3 0LS Telephone: 01874 711661 Fax: 01874 712554





If you are still dissatisfied at the end of the review, you may complain to the Information Commissioner, who can be contacted at the following address:

Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SH9 5AF

Yours sincerely

Carol Shillabeer Director of Nursing

Encs

Internally within Powys teach Health Board

1. What is the average waiting time for a patient from referral to first appointment with a specialist?

Powys tHB work to a component wait of 10 weeks for new appointments, with patients having to be treated within 26 week RTT target in line with the Consolidated RTT Waiting Time Rules issued by the Welsh Assembly Government.

2. Do you run clinics specialising in sleep disorders? If so, how often are they held?

None held in Powys - where patients are identified as requiring these tests patients are referred on to appropriate Health Board?

3. Do you have any medical staff who specialise in sleep disorders? If so, how many sessions do they work on a monthly basis?

None

4. What treatment options do you offer to patients diagnosed with obstructive sleep apnoea?

This would be arranged by the treating external Health Board

5. In relation to treatment options, do you provide CPAP machines to patients diagnosed with sleep apnoea?

If required these would be arranged by the treating external Health Board

In respect of external providers the services we commission are for patients to be treated within the Welsh Target of 26 weeks referral to treatment and or sooner if clinically prioritized by the consultant. Unfortunately the clinic details, frequency etc is not held within Powys.



Christine Chapman Chair Petitions Committee National Assembly for Wales Cardiff Bay Cardiff CF99 1NA

Ein cyf / Our ref: 157/10/FOI **Eich cyf / Your ref**: P-03-156

Dyddiad / Date: 17th June 2010

Christine.Chapman@wales.gov.uk

Dear Ms Chapman

Further to your request for information dated 25th May 2010 concerning sleep apnoea which was received at our offices on 1st June 2010, I am pleased to provide the response below.

You asked us:

- 1) What is the average waiting time for a patient from referral to first appointment with a specialist?
- 2) Do you run clinics specialising in sleep disorders? If so how often are they held?
- 3) Do you have any medical staff who specialise in sleep disorders? If so, how many sessions do they work on a monthly basis?
- 4) What treatment options do you offer to patients diagnosed with obstructive sleep apnoea?
- 5) In relation to treatment options, do you provide CPAP machines to patients diagnosed with sleep apnoea?

Our response:

- 1) Betsi Cadwaladr University Health Board (BCUHB) provides Sleep Apnoea services across the health board with the majority of patients managed via the West (Ysbyty Gwynedd) and East (Ysbyty Maelor) specialist services. We also have established links with tertiary consultants at Aintree, Liverpool for the small number of patients requiring BPAP and higher specialist services. The average waiting time in the West is 26 weeks and in the East is 32 weeks.
- 2) Yes. These clinics are held monthly in the West and weekly in the East.
- 3) Yes, the specialist service is supported by 4 consultants from ENT and Respiratory Medicine, providing approximately 12 sessions per month.
- 4) Last year BCUHB redesigned the sleep apnoea pathway to provide earlier identification of patients with a positive diagnosis and in need of CPAP management. Patients are initially sent a questionnaire which divides them into Inpatient or Outpatient category. Outpatient appointments are at 6 weeks, approximately 50% of patients are

able to be diagnosed through this route and proceed to treatment without requiring an Inpatient admission for further diagnostics.

If a patient goes onto an Inpatient waiting list for a sleep study test, this involves an overnight stay in hospital to monitor sleep patterns. The outcome of this sleep study is then assessed by the specialised sleep team who decide on the appropriate form of treatment. A CPAP machine (Continuous Positive airway pressure) is the most likely treatment provided to aid respiratory ventilation during sleep; however mandibular devices and some surgical treatments are also offered if CPAP is not suitable / tolerated. Patients not diagnosed with sleep apnoea may be managed for other clinical issues identified such as Ear Nose and Throat snoring conditions, drug or alcohol problems, obesity or psychological problems which require to be treated.

5) Yes.

If you are dissatisfied with the way the Health Board has handled your request for information, you can request a review by writing to:

Complaints Manager Betsi Cadwaladr University Local Health Board Ysbyty Gwynedd, Penrhosgarnedd, Bangor LL57 2PW

If you remain dissatisfied with the handling of your request or complaint, you have a right of appeal to the Information Commissioner at:

The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF.

Telephone: 08456 30 60 60 or 01625 54 57 45 Website: http://www.ico.gov.uk

There is no charge for making an appeal.

If you require any further assistance, please do not hesitate to contact me on 01978 346538.

Yours singerely

Mary Burrows
Chief Executive



Ysbyty'r Eglwys Newydd Whitchurch Hospital

Park Road, Whitchurch. Cardiff, CF14 7XB Phone 029 2069 3191 Heol Parc, Yr Eglwys Newydd Caerdydd, CF14 7XB Ffôn 029 2069 3191

Eich cyf/Your ref: Ein cyf/Our ref: Welsh Health Telephone Network: Direct Line/Llinell uniongychol: 02920 745684

Jan Williams OBE Chief Executive

30th June 2010

Christine Chapman Chair, Petitions Committee National Assembly for Wales Cardiff Bay Cardiff CF99 1NA

Your Ref: P-03-156 Our Ref: JW/jb/06/251

Dear Ms Chapman

PETITION: SLEEP APNOEA

I am writing in response to the Petitions Committee request for information relating to Sleep Apnoea. In order to provide the response in context, I have provided some background to the current unacceptable position regarding this service together with details of improvement to ensure we meet NICE requirements.

In July 2004, Cardiff and Vale NHS Trust took the unusual step of writing to all LHB Chief Executives and Medical Directors, informing them that the Sleep Apnoea service was closed to **new routine referrals** for clinical governance reasons.

At the time of writing, Cardiff and Vale UHB provides consultation, diagnostic testing and treatment for those patients with a high Epworth score (sleep disturbance score). Referrals without an Epworth Sleepiness assessment score, or those who do not meet the high risk category are returned to the referring GP.

Question 1: What is the average waiting time for a patient from referral to first appointment with a specialist?

The waiting time is relatively short. It is normally a maximum of 4 weeks for diagnostic testing. From referral, diagnosis and then treatment, the wait averages at 18 weeks.



Question 2: Do you run clinics specialising in sleep disorders? If so, how often are they held?

One clinic per week is dedicated to sleep disorders.

Question 3: Do you have any medical staff who specialise in sleep disorders? If so, how many sessions do they work on a monthly basis?

Patients who need to be seen urgently are assessed by a Specialist Respiratory Physician with an interest in Sleep Disordered Breathing.

Question 4: What treatment options do you offer to patients diagnosed with obstructive sleep apnoea?

Testing is undertaken by overnight oximetry, a small number of more complex patients will require limited polysomnography. There is no indication for full polysomnography in the diagnosis of Obstructive Sleep Apnoea.

Initially lifestyle advice may be given, such as diet, exercise during the day, weight loss etc. If this is not successful, then level two treatment is recommended: airway management, nasal treatment and application of mandibular advancement devices. Referral to Ear Nose and Throat Services may be necessary and successful in some cases.

Question 5: In relation to treatment options, do you provide CPAP machines to patients diagnosed with sleep apnoea?

Level 3 treatment is the assessment and prescription of CPAP. This is carefully trialled and titrated according to the patients' toleration and pressure requirements. Patients are regularly followed up through the outpatient services.

The UHB 2010/11 Operational Plan includes provision to expand the service to meet the NICE Referral criteria, involving the appointment of a specialist consultant and clinical support staff. This expanded service will be available in the next 3-4 months, subject to a successful recruitment process.

I do hope this information answers your queries. If you require further information, please do not hesitate to contact me.

Yours sincerely

Jan Williams
Chief Executive



Response from Cwm Haf LHB



Your ref/eich cyf: Our ref/ein cyf: Date/dyddiad: Tel/ffôn: P-03-156 SCW/KF/RT 24/06/10 01443 443582 01443 443159

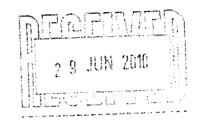
Fax/ffacs: Email/ebost:

Dept/adran:

Acute Division

Private & Confidential

Christine Chapman
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
CARDIFF
CF99 1NA



Dear Ms Chapman

Further to your request to Mrs Foster, Chief Executive Cwm Taf Health Board, for information regarding Sleep Apnoea on the 25 May 2010, I trust that this data meets with your needs.

This Service is run within both the Royal Glamorgan Hospital and Prince Charles Hospital and is led by a Consultant Physician with a specialist interest at each site.

In answer to your queries:

1. What is average waiting time for a patient from referral to first appointment with a specialist?

The Medicine South (Royal Glamorgan Hospital) Sleep Apnoea Service is designed as follows:

Referrals are reviewed by the Specialist Consultant and diagnostic requests are made for those patients considered to potentially have Sleep Apnoea. Once the Diagnostic is completed and the result available, the Specialist Consultant will decide if an outpatient appointment is required or a further diagnostic investigation is required before the outpatient appointment.

Cont'd/....

Return Address:

This process can therefore range from a waiting time of a minimum of 15 weeks, with an Oximetry diagnostic result, to a maximum of 36 weeks if the patient has been referred for further diagnostic investigations such as Autoset/Stardust.

The Medicine North (Prince Charles Hospital) Sleep Apnoea Service is designed as follows:

Patients are seen first by the Specialist Consultant in an outpatient appointment, then investigations are requested if necessary. If investigations are positive, patients are placed on waiting list for treatment with CPAP without further follow up by a Consultant. Therefore the typical wait lies between 15-20 weeks to be seen by Consultant, with Pulse Oximetry done the same night. Waiting time for limited channel sleep studies now sits at 18 weeks.

2. Do you run clinics specialising in sleep disorders? If so, how often are they held?

The Medicine South Service runs an average of 1.5 specialist clinics per month.

Medicine North have a monthly session per month, although Sleep Apnoea patients may also be seen in a General Respiratory clinic by the specialist consultant.

3. Do you have any Medical Staff who specialise in sleep disorders? If so, how many sessions do they work on a monthly basis?

There are 2 WTE Specialist Consultants within the Medical Directorate of Cwm Taf Health Board, one based at Prince Charles Hospital and one based at the Royal Glamorgan Hospital.

4. What treatment options do you offer to patients diagnosed with obstructive sleep apnoea?

All patient's with confirmed diagnosis who are significantly symptomatic for moderate and above sleep apnoea are offered a trial of CPAP first line and then if patient declines CPAP or the trial is unsuccessful then treatment with Mandibular Advancement Device is offered.

5. In relation to treatment options, do you provide CPAP machines to patients diagnosed with sleep apnoea?

Yes, CPAP machines are provided to patients diagnosed with sleep apnoea, subject to patient tolerance and providing funding is available to secure appropriate number of machines to meet demand on the Service; approximate demand is 200 per annum for the Health Board.

I hope that this information meets your requirements; if however, you require anything further then please do not hesitate to contact me.

Yours sincerely

Mr Robert Thomas

Divisional General Manager

A Magier

Acute Division





Reply to: ABMU Health Board Headquarters, 1 Talbot Gateway, Port Talbot, SA12 7BR.

2 (01639) 683302

WHTN: 0 1787 3302

David.Sissling@wales.nhs.uk

9th July 2010

Ms. Christine Chapman, Chair, Petitions Committee, National Assembly for Wales, Cardiff Bay, Cardiff, CF99 1NA. PRINTING 200

Our Ref: DS/AG/CBT

Your Ref: P-03-156

Dear Christine,

Re: Sleep Apnoea

I refer to your letter, dated 25th May 2010, regarding Sleep Apnoea. Please find the ABMU Health Board response below:

1.	What is the average waiting time for a patient from referral to first appointment with a specialist?	22 - 26 weeks
2.	Do you run clinics specialising in sleep disorders? If so, how often are they held?	1 – 2 X Weekly
3.	Do you have any medical staff who specialise in sleep disorders? If so, how many sessions do they work on a monthly basis?	16 sessions
4.	What treatment options do you offer to patients diagnosed with obstructive sleep apnoea?	Lifestyle changesWeight reduction adviceCPAPMandibular devices
5.	In relation to treatment options, do you provide CPAP machines to patients diagnosed with sleep apnoea?	Yes, in accordance with NICE guidance

Contd./.....

Bwrdd Iechyd ABM yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Abertawe Bro Morgannwg ABM University Health Board is the operational name of Abertawe Bro Morgannwg University Local Health Board Pencadlys ABM / ABM Headquarters, 1 Talbot Gateway, Port Talbot, SA12 7BR. Ffon / Tel: (01639) 683344 If you require any further assistance please do not hesitate to contact me.

Yours sincerely,

pp Alex Howevs David Sissling

Chief Executive



Ref: AG/JP/Iz Direct Line: 01495 765072 6 July 2010

Ms Christine Chapman Chair Petitions Committee National Assembly for Wales Cardiff Bay Cardiff CF99 1NA



Dear Ms Chapman

Re: Petition - Sleep Apnoea

I am writing further to your correspondence of 25 May 2010 inviting information on behalf of the Petitions Committee about sleep services currently provided by Aneurin Bevan Health Board.

Your specific questions are considered below.

1. What is the average waiting time for a patient from referral to first appointment with a specialist?

The current sleep pathway is under review due to the differential wait times between the hospitals. Aneurin Bevan's overall average wait time is 27 weeks. However, there is a much longer wait period for patients referred to the south of the county due to the specialist diagnostic Polysomnography service provided. Work is being undertaken with the key clinicians to improve the pathway in South Gwent.

The proposed pathway will enable shorter waiting times to essential diagnostic physiological tests prior to the Consultant appointment. During this period the patient will be under the care of a specialist nurse or physiologist, the diagnostic stage is an essential pre-requisite to enable the Consultant to agree the appropriate treatment with the patient.

Cont/d.....

Bwrdd Iechyd Aneurin Bevan Pencadlys Bloc A, Tŷ Mamhilad, Ystad Parc Mamhilad, Pontypŵl, Torfaen. NP4 0YP

Ffôn: 01873 732732 (prif switsfwrdd)

e-bost: enquiries@aneurinbevanlhb.wales.nhs.uk

Aneurin Bevan Health Board Headquarters Block A, Mamhilad House. Mamhilad Park Estate, Pontypool, Torfaen, NP4 OYP Telephone: 01873 732732

e-mail:

enquiries@aneurinbevanlhb.wales.nhs.uk



Bwrdd Iechyd Aneurin Bevan yw enw gweithredol Bwrdd Iechyd Lleol Aneurin Bevan Aneurin Bevan Health Board is the operational name of Aneurin Bevan Local Health Board Unfortunately, until this new pathway is fully implemented the average waiting time stated is an estimate based upon the 'old' way of working. The new pathway will 'stream' direct referrals to the specialist service and enable routine patients to receive the core service more efficiently. It is worth noting that the Sleep service receives a large number of referrals from the Consultants and therefore the patient is already under clinical supervision whilst waiting for a specialist appointment.

2. Do you run clinics specialising in sleep disorders? If so, how often are they held?

Consultant led clinics specialising in sleep disorders run at Newport Chest Clinic, St Woolos Hospital a weekly basis. They comprise a mix of new and follow up patients.

A full time Sleep Nurse Specialist runs two weekly clinics at Newport Chest Clinic to review patients receiving CPAP treatment. Additionally, the CNS and a Chest Clinic RGN run several sessions weekly to initialise CPAP treatment.

At Nevill Hall Hospital, sleep patients are seen by Respiratory consultants in their general respiratory outpatient clinics. The Nevill Hall service is supported by respiratory physiologists who organise home sleep studies, initiate CPAP therapy and support after care.

3. Do you have any medical staff who specialise in sleep disorders? If so, how many sessions do they work on a monthly basis?

Dr Melissa Hack, Consultant in Respiratory & General Medicine, Newport Chest Clinic is the lead consultant in Aneurin Bevan Health Board with specialist training in sleep disorders. She provides a weekly dedicated sleep outpatient clinic (1 session) for new and follow up patients. She has one associated administrative session for reporting sleep investigations arising from home or inpatient sleep studies.

4. What treatment options do you offer patients diagnosed with obstructive sleep apnoea?

Treatment options include:-

- General health improvement advice including weight loss and offer of referral to a dietician. The GP has usually gone through this prior to referral. Education and advice about healthy sleep habits.
- General simple specific therapy e.g. steroid nasal spray for congestion, positional management for supine obstructive sleep apnoea.
- Mandibular devices for mild obstructive sleep apnoea- the patient has to purchase these shelf made from the internet or custom built from their dentist. They are not available on the NHS.
- Continuous positive airway pressure is provided as per NICE guidelines for moderate to severe obstructive sleep apnoea and in some milder cases with excessive sleepiness.
- Surgical options in some cases to be referred to ENT

Cont/d.....

6 July 2010

5. In relation to treatment options, do you provide CPAP machines to patients diagnosed with sleep apnoea?

Continuous positive airway pressure is provided as per NICE guidelines for moderate to severe obstructive sleep apnoea and in some milder cases with excessive sleepiness.

I hope the above information is helpful. Should you require anything further, Celia Satherley, Directorate Manager – Cardiology & Respiratory Medicine will be pleased to assist you. Her direct telephone line at the Royal Gwent Hospital is 01633 238548.

Yours sincerely

And quan

Dr Andrew Goodall Prif Weithredwr/ Chief Executive Bwrdd Iechyd Aneurin Bevan/ Aneurin Bevan Health Board



Ein cyf/Our ref:

TP/elc

Gofynnwch am/Please ask for:

Trevor Purt, Chief Executive

Rhif Ffôn /Telephone:

01437 771220

Ffacs/Facsimile:

01437 771222

E-bost/E-mail:

Trevor.purt@wales.nhs.uk

Hywel Dda Health Board Headquarters: Merlins Court, Winch Lane, Haverfordwest, Pembrokeshire, SA61 1SB

Tel Nr: (01437) 771220

Hywel Dda Health Board Headquarters Medins Court, Winch Lane, Haverfordwest,

Pembrokeshire, SA61 1SB Tel Nr: (01437) 771220

30 June 2010

Christine Chapman Chair, Petitions Committee National Assembly for Wales Cardiff Bay CF99 1NA

Dear Mrs Chapman,

Petition - Sleep Apnoea

Further to your letter of 25th May 2010, please find below the following information in respect of services for patients with obstructive sleep apnoea in the Hywel Dda area.

For ease of reference, this response is structured to the 5 specific questions in your letter:

- 1. The average waiting time between referral and first appointment with a specialist is currently 12 weeks.
- 2. We provide a weekly clinic dedicated for patients with sleep disordered breathing (SBD) and ventilatory failure at Prince Philip Hospital in Llanelli. Whilst we do not have direct neurology support within the Health Board, the Consultant who specialises in this area will treat conditions such as periodic limb movement disorder, restless legs/Ekboms disease and narcolepsy. Consequently, only a small number of patients are referred to Neurology services at Morriston Hospital.

Cont/...

Pencadlys Bwrdd Techyd Hywel Dda Llys Myrddin, Lôn Winch, Hwlfferdd, Sir Benfro, SA61 1SB Rhif Ffôn: (01437) 771220 Rhif Ffacs: (01437) 771222 Hywel Dda Heaith Board Headquarters Merlins Court, Winch Lane, Haverfordwest, Pembrokeshire, SA61 1SB Tel Nr. (01437) 771220 Fax Nr. (01437) 771222 Cadeirydd / Chairman Mr Chris Martin

Prif Weithredwr /Chief Executive Mr Trevor Purt



-2-

- 3. The lead Consultant has a particular interest in SDB. He holds a research degree (MD) in this area and supervises a higher degree for postgraduate students. It is interesting to note that all MDs awarded in sleep apnoea in Wales have originated via this source. The clinical team is very active in research and are supported by a dedicated sleep / NIV nurse and a technician with a special interest in SDB. The lead Consultant has 4 sessions per month dedicated to this service in his current job plan.
- 4. The main treatment options include CPAP in accordance with NICE guidance. Some patients are referred to Swansea for mandibular advancement devices and occasionally we offer bilevel ventilation. In very difficult cases, patients are referred for bariatric surgery. Modafanil is recommended for residual sleepiness when established on CPAP. All the above fall within national guidelines (eg. SIGN/BTS).
- 5. We currently have over 1100 patients on CPAP therapy.

I trust the information detailed above is useful to the Committee although we would be happy to assist with any further enquiries should this be required.

Yours sincerely

Trevor Purt Chief Executive



Ein cyf/Our ref:

TP/elc

Gofynnwch am/Please ask for:

Trevor Purt, Chief Executive

Rhif Ffon /Telephone:

01437 771220

Ffacs/Facsimile:

01437 771222

E-bost/E-mail:

Trevor.purt@wales.nhs.uk

Hywel Dda Health Board Headquarters Merlins Court, Winch Lane, Haverfordwest,

Pembrokeshire, SA61 1SB Tel Nr: (01437) 771220

Hywel Dda Health Board Headquarters Medins Court, Winch Lane, Haverfordwest,

Pembrokeshire, SA61 1SB Tel Nr: (01437) 771220

30 June 2010

Christine Chapman Chair, Petitions Committee National Assembly for Wales Cardiff Bay CF99 1NA

Dear Mrs Chapman,

Petition - Sleep Apnoea

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Cont/...



- 2 -

- 3. The lead Consultant has a particular interest in SDB. He holds a research degree (MD) in this area and supervises a higher degree for postgraduate students. It is interesting to note that all MDs awarded in sleep apnoea in Wales have originated via this source. The clinical team is very active in research and are supported by a dedicated sleep / NIV nurse and a technician with a special interest in SDB. The lead Consultant has 4 sessions per month dedicated to this service in his current job plan.
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- 5. We currently have over 1100 patients on CPAP therapy.

I trust the information detailed above is useful to the Committee although we would be happy to assist with any further enquiries should this be required.

Yours sincerely

Trevor Purt Chief Executive

Rhif Ffacs: (01437) 771222

Response from the Minister for Health and Social Services

Edwina Hart MBE OStJ AM

Y Gweinidog dros lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services

Our ref:

EH/03431/10

Your ref:

P-03-156

Christine Chapman AM Chair - Petitions Committee

committee.business@Wales.gsi.gov.uk



Llywodraeth Cynulliad Cymru Welsh Assembly Government

Bae Caerdydd Caerdydd CF99 1NA Llinell Ymholiadau Cymraeg: 0845 010 4400 Ffacs: 029 2089 8131 E-Bost:Gohebiaeth.Edwina.Hart@cymru.gsi.gov.uk

> Cardiff Bay Cardiff CF99 1NA English Enquiry Line: 0845 010 3300 Fax: 029 2089 8131

E-Mail:Correspondence.Edwina.Hart@Wales.gsi.gov.uk

2 0 October 2010

Dear Christine

Thank you for your letter of 15 October on behalf of the Petitions Committee about sleep apnoea services.

The National Leadership and Innovation Agency for Healthcare (NLIAH) required Local Health Boards (LHBs) to submit their audit returns detailing compliance against the Service Development and Commissioning Directives for Respiratory Conditions by 30 September.

NLIAH are currently analysing and compiling the audit data on an individual LHB and all-Wales basis and the outcome of audit compliance will be published in early November.

en.

Response from the petitioners

03-07-2011 Welsh Sleep Apnoea Society

Rhodri

I have now had a chance to look through the papers sent to me and would make the following comments in relation to the Aneurin Bevan Trust:

The overall average for the process from GP referral to commencing treatment for CPAP in South Gwent in in excess of **2 years** and the comments relating to diagnostic polysomnography services should not really have an impact as this as this is not a routine procedure as it affects on average 1 or 2 patients per month

The work undertaken to improve the pathway in South Gwent and reduce the differential waiting times between hospitals has 'gone quiet' and it is believed that there should be some deadline given for completion. Deliberations on sharing workloads between Nevill Hall and St Woolos, is ongoing but is unfortunately proceeding at a slow pace. The comments that the proposed pathway will enable shorter waiting times to essential diagnostic physiological tests prior to the Consultant appointment and the comment that during this period the patient will be under the care of a specialist nurse is not true, unfortunately.

I am not in a position to clarify summaries from other Local Health Boards unfortunately, but if they mirror the situation in Gwent, it does make one wonder on their total accuracy.

I trust these comments are of value to you. With all best wishes

Angela

Angela J Parry, MBE Honorary Secretary, Welsh Sleep Apnoea Society