

Wales Familial Hypercholesterolaemia (FH) Forum - for individuals and families with inherited high cholesterol.

31st October 2008

Clinical Guidelines for FH diagnosis and management supports work in Wales

In August 2008, guidelines were published on the diagnosis and management of FH by NICE – the National Institute of Health and Clinical Excellence, the Government agency responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

The guidelines support the establishment of a family cascade screening programme; a system of identifying and diagnosing people through known relatives. The work has been on-going for over two years and is produced by an advisory group of experts involved in the area.

This is fantastic endorsement for the efforts of the team involved in the south Wales pilot project and further supports the effort to secure a Wales wide service to find people and families who have FH and are not currently diagnosed.

Some of the other recommendations by the NICE guidelines are as follow:

- A family history should always be obtained from an individual being investigated for FH to determine if a dominant pattern of inheritance is present.
- All individuals with FH should be referred to a specialist with expertise in FH for confirmation of diagnosis and initiation of cascade testing.
- Cascade testing using a combination of lipid concentration measurement and DNA testing should be used to identify relatives of index cases with a clinical diagnosis of FH.



NICE guidelines publications for FH

- The establishment and use of a nationwide family based follow-up system is recommended to enable comprehensive identification of affected individuals.
- Diagnosis and treatment of children from age 10 onwards is recommended.

Full details of the recommendations are available in various formats on the FH Forum website, including a readable guide intended for patients and families. Click onto the 'news & events' section: www.fhwales.co.uk or contact us at the details below for a paper copy.

PLEASE NOTE OUR NEW CONTACT DETAILS!

Genetic Interest Group (c/o Miss Buddug Williams)
206b Neuadd Meirionnydd, Heath Park, Cardiff CF14 4YS
Tel: 029 20 68 76 46 Email: williamsbg@cf.ac.uk

The Genetic Interest Group (GIG) is an umbrella charity for a range of genetic conditions including FH. Buddug is the GIG officer for Wales and links families, health professionals and voluntary groups with an interest in FH. Registered charity number: 1114195.

Carwyn Jones AM supports the FH Family Forum



The September meeting of the Forum was in the Princess of Wales of Hospital, Bridgend. Carwyn Jones AM for Bridgend and member of the Assembly Government joined the event and praised the work of the pilot project team. He also supported the efforts in Wales to develop new health services to prevent ill-health and save lives.

Dr Ian McDowell presented the proposed Business Plan for FH in Wales that had been submitted to the Assembly Government. A summary copy of the case

Above: Carwyn Jones AM talks to Shirley Adams, Forum member & Suzanne Watkins, Specialist Nurse at the Forum in Bridgend.

is also available on the FH Forum website: www.fhwales.co.uk under 'news & events' or contact us for a paper copy. The event was well attended by over 45 Forum members and friends.



Great media coverage for FH in Wales



Over the past few months, Forum members have been working to ensure a high profile in the media for FH matters. To coincide with the publication of the NICE guidelines, we received extensive coverage in the Western Mail and Echo newspapers, the Brecon & Radnor Express and a second package on ITV Wales' evening news 'Wales Tonight'. Our thanks go out Elin Collins and family, Phil Rowlands, Roger Evans & Dr Alan Rees for their contributions and everyone who has helped us. Archived details are on www.fhwales.co.uk



Your Forum Needs Your Ideas For 2009!

Plans for future Forum events in 2009 are taking into consideration what Forum members want out of them. We hope to have an event discussing matters on FH in children and young people, and are also organizing events further afield in both west and north Wales. If you have ideas or suggestions on our future work area, we would be very pleased to hear from you either through the website, email or telephone!



Grŵp Cydlynu Rhwydwaith y Galon
Cardiac Networks Co-ordinating Group

A British Heart Foundation Heart Support Group

Wales Familial Hypercholesterolaemia (FH) Forum

FH - the way forward in Wales

- How can we deliver the NICE clinical guidelines?

You are invited to:

**Evening Reception at the Cwrt in the Senedd,
National Assembly for Wales, Cardiff Bay CF99 1NA**
Tuesday the 2nd of December 2008
6.15pm – 7.30pm

Hosted by Helen-Mary Jones AM

Speakers include:

Dr Ian McDowell, FH Special Interest Group

Dr Phil Thomas, Lead Cardiac Clinician for Wales

Dr Mike Knapton, Director of Prevention & Care, British Heart Foundation

Organised by the Genetic Interest Group on behalf of the FH Family Forum

To continue building on the level of support the FH Forum has gained towards achieving a commissioned service across Wales, the next Forum event will be an evening Reception at the National Assembly in Cardiff. This work builds on earlier events by the Forum in the Assembly; we hope that this will gain further support and confidence in achieving a commissioned service across Wales for FH families.

This letter is an invitation for you and your family to join us. There will be opportunities for you to meet up with politicians, civil servants, health professionals and also to hear about the latest developments in achieving a Wales-wide service. The British Heart Foundation and Heart UK will also be present. There will also be opportunity for discussion. There will be light refreshments available.

We ask you also to contact your elected representatives in the Assembly and ask them to join us. It is vital to ensure their continued support for this area, particularly for a health service that will intervene early and prevent illness - investing in long-term health. Overleaf is a letter template which you might like to use in contacting your AM, either by letter, email or telephone.

We sincerely hope you will be able to joining us for the Forum Reception. *Numbers are limited to this event, please contact us at the details below to confirm your attendance and to assist arrangements & security. Please bring this invitation with you on the evening.*

We hope you can join us and look forward to your company.

Please confirm your attendance to:

Miss Buddug Williams, Genetic Interest Group

206b Neuadd Meirionnydd, Heath Park, Cardiff CF14 4YS

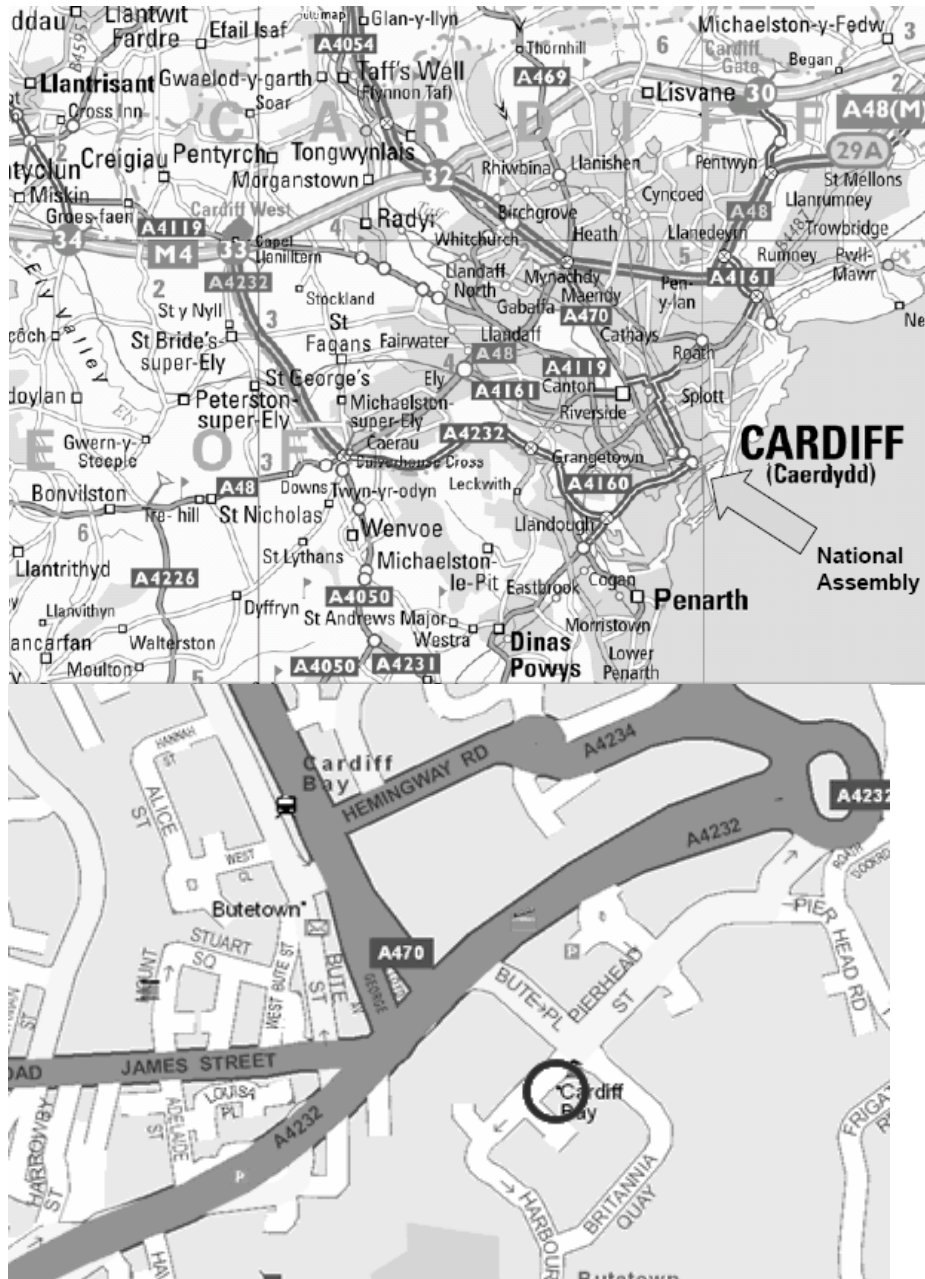
Tel: 029 20 68 76 46 Email: williamsbg@cf.ac.uk

Familial Hypercholesterolaemia (FH) – the way forward in Wales

How can Wales deliver the NICE clinical guidelines?

Evening Reception at the Cwrt in the Senedd, National Assembly for Wales, Cardiff Bay CF99 1NA
Tuesday the 2nd of December 2008 from 6.15pm – 7.30pm

****Please RSVP and bring your invitation with you.**



Directions

By car

- From the West: Leave M4 at junction 33 & follow signs for Cardiff Bay / Techniquet on the A4232.
- From the East: Leave M4 at junction 29 onto the A48M & follow signs for Cardiff Bay.
- From the North: Along the A470, follow signs towards Cardiff Bay through the city centre.

By bus: Cardiff Buses numbers 7,8 & 9 stop by Assembly building.

By train: Cardiff Bay train station is a five minute walk from the Assembly building.

Parking at the Assembly: All car parks are pay & display.

The nearest car park is the multi-storey on Pierhead St., which is closest to the Assembly a car park is also at the Red Dragon Centre (Odeon cinema), Hemingway Rd. A car park is also at Stuart St (opposite Techniquet) another car park is available at Havannah St (St David's Hotel)

Contacting your Assembly Member

- Below is a draft letter to your AM you may wish to use, but please personalise it in your own words. Overleaf is a list to help you identify your AMs.
 - Assembly Members may also be contacted through email. The standard address is: `firstname.secondname@wales.gov.uk` e.g. `rhodri.morgan@wales.gov.uk`
 - If you receive a reply, please let us know!
 - ***If you would like further information or assistance in contacting your elected representative, please contact Buddug Williams on 029 20 68 76 46.***
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Your address

[Name] AM
National Assembly for Wales
Cardiff Bay CF99 1NA

Dear [name of assembly member] AM,

I am writing to ask you for your help and support to ensure myself, my family and other families with inherited high cholesterol can benefit from a diagnosis and healthcare to help keep us in good health, not let us develop heart disease and to save many lives.

I have Familial Hypercholesterolaemia (FH), a genetic condition causing high cholesterol levels that can lead to early coronary heart disease which can have tragic consequences. It is a genetic condition, meaning that family members are also at risk.

[add some details here to high-light the effect of FH on your health and family history].

Modern medications for FH and specific lifestyle information particularly to avoid smoking exercise are very effective in preventing heart disease in FH and in keep people healthy and saving lives. However people can only receive this treatment once they have been diagnosed. All too often, this diagnosis may only be made after a heart attack has already occurred.

[describe your own situation – e.g. have your cholesterol levels decreased, or have you stopped smoking since you have been attending the specialist lipid clinic?]

In Wales there is no established health service to offer diagnosis and management to people with and at risk of FH, despite the fact that it can be easily and effectively treated and controlled. It is vital that people with this condition get the diagnosis and care that will save their lives and the lives of their families.

Please will you write on my behalf to the Health Minister Mrs Edwina Hart to ask how the Welsh Assembly Government is ensuring my relatives and families with FH like mine can be diagnosed and treated appropriately and timely.

[if you have already contacted them last year about better services for FH, please remind them of this].

Please join me at an evening reception in the Cwrt, Senedd in Cardiff Bay on Tuesday the 2nd of December 2008 from 6.15 – 7.30pm to find out more about FH and how we can work together to save lives and safeguard the health of people like myself and my family who have FH.

I look forward to hearing from you soon,

Yours sincerely,

NAME

Contacting your Assembly Member

If you have Internet access, go to: www.assemblywales.org/memhome/member-search and type in your postcode to find out who are your Assembly Members.

Or

Below is a list of Assembly Members.

Find your constituency (where you live) in the left column.

The name of your Constituency AM is in the middle column. The four Regional AMs for your area are in the right hand column. You may therefore contact all five AMs.

If you have any comments, are unsure of who are your AMs or would like some assistance, please contact Buddug Williams on: 029 20 68 76 46

The Parties are: Conservative - Con Independent - I Labour - Lab Lib Dem - LD
Plaid Cymru - PC

Mid and West Wales	CONSTITUTENCY AMs:	REGIONAL AMs:
Brecon & Radnorshire	Kirsty Williams (LD)	Alun Davies (Lab)
Carmarthen East & Dinefwr	Rhodri Glyn Thomas (PC)	Joyce Watson (Lab)
Carmarthen West & S Pembs	Angela Burns (Con)	Nerys Evans (PC)
Ceredigion	Elin Jones (P)	Nick Bourne (Con)
Llanelli	Helen Mary Jones (PC)	
Meirionnydd	Lord Elis-Thomas (P)	
Montgomeryshire	Mick Bates (LD)	
Preseli / Pembrokeshire	Paul Davies (Con)	
South Wales West	CONSTITUTENCY AMs:	REGIONAL AMs:
Aberavon	Brian Gibbons (Lab)	Alun Cairns (Con)
Bridgend	Carwyn Jones (Lab)	Peter Black (LD)
Gower	Edwina Hart (Lab)	Bethan Jenkins (PC)
Neath	Gwenda Thomas (Lab)	Dai Lloyd (PC)
Ogmore	Janice Gregory (Lab)	
Swansea East	Val Lloyd (Lab)	
Swansea West	Andrew Davies (Lab)	
South Wales Central	CONSTITUTENCY AMs:	REGIONAL AMs:
Cardiff Central	Jenny Randerson (LD)	David Melding (Con)
Cardiff North	Jonathon Morgan (Con)	Andrew Davies (Con)
Cardiff South & Penarth	Lorraine Barrett (Lab)	Leanne Wood (PC)
Cardiff West	Rhodri Morgan (Lab)	Christopher Franks (PC)
Cynon Valley	Christine Chapman (Lab)	
Pontypridd	Jane Davidson (Lab)	
Rhondda	Leighton Andrews (Lab)	
Vale of Glamorgan	Jane Hutt (Lab)	
South Wales East	CONSTITUTENCY AMs:	REGIONAL AMs:
Blaenau Gwent	Trish Law (Ind)	William Graham (Con)
Caerphilly	Jeffrey Cuthbert (Lab)	Mohammad Asghar (PC)
Islwyn	Irene James (Lab)	Mike German (LD)
Merthyr Tydfil & Rhymney	Huw Lewis (Lab)	Jocelyn Davies (P)
Monmouth	Nick Ramsay (Con)	
Newport East	John Griffiths (Lab)	
Newport West	Rosemary Butler (Lab)	
Torfaen	Lynne Neagle (Lab)	