



Grŵp Cydlynu Rhwydwaith y Galon
Cardiac Networks Co-ordinating Group

8th February 2007

Name
Address 1
Address 2
Postcode

Dear Name

**Forum for patients with FH (Inherited High Cholesterol)
Awareness Day Thurs 1st March 2007,
National Assembly for Wales, Cardiff Bay 12.30 – 3.00**

It is now clear that treatment for those with FH (familial hypercholesterolaemia) is very effective at preventing heart attacks and saving lives. We know that identifying family members who have inherited the condition can prevent early heart disease. Despite this, the NHS in Wales has only very basic services for people and families with FH. This major failure of the NHS can be improved with a relatively small investment in services. To do this, we need to raise awareness about FH and highlight the importance of a coordinated health service involving specialist nurses giving information and offering cascade screening and treatment for families with FH.

We are having an awareness day at the National Assembly for Wales, Cardiff Bay on the 1st of March and we would like you to join us. Many different groups will be there including health professionals, health service planners, charities, politicians and most importantly people with FH. A programme is enclosed with further details. Please make time for this event, your input is important.

To gain the attention of Assembly Members to join us at the event, we ask that you contact them directly by letter or by visiting them at their constituency surgery. Details of how to do this are attached with a template letter and points that you may wish to include that relate to FH. However please also add your own personal comments.

Please put this event in your diary and confirm your attendance with us by returning the reply slip to the Genetic Interest Group office (address below) – and join us in our efforts to get FH on the NHS agenda - to improve health and save lives.

We look forward to seeing you on the 1st of March.

With best wishes,

Yours sincerely,

Dr Ian McDowell
Chair of FH Special Interest Group

Miss Buddug Williams
Genetic Interest Group Officer for Wales

Genetic Interest Group (c/o Miss Buddug Williams)
Wales Gene Park, Medicentre,
Heath Park, Cardiff CF14 4UJ
Tel: 029 20 68 21 40 Email: williamsjk1@cf.ac.uk

The Genetic Interest Group (GIG) is an “umbrella” charity for patient support groups for a range of genetic conditions including FH. Buddug is the GIG officer for Wales and helps link health professionals and voluntary groups with an interest in FH.



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Cardiac Networks Co-ordinating Group

Wales Familial Hypercholesterolaemia (FH) Forum Awareness Day at the National Assembly for Wales

**Crickhowell House, National Assembly for Wales, Pierhead St, Cardiff Bay
Thursday 1st of March 2007, 12.30pm Committee Room 22**

12.30 pm **Introduction and update of FH in Wales**
Dr Alan Rees, Consultant, Lipid Clinic, UHW

Ms Helen Mary Jones, AM for Mid & West Wales

Light lunch & refreshments, and discussion with Assembly Members

2.00 pm Guest speaker

Professor Julian Sampson, Wales Gene Park, Cardiff University
"Why we need an FH coordinator in Wales"

Open session, questions & answers
Chaired by Dr Ian McDowell, Convenor FH Special Interest Group,

3.00pm Closing remarks

Please make time for this event to help raise the awareness of proper diagnosis and treatment of FH. Join us in our efforts to get FH on the NHS agenda - to improve health and save lives.

Write to or contact your Assembly Members and invite them to join us at the event so that they can learn more about FH and how they can help.

There is no charge to attend this event; but we would ask that you confirm your attendance with us by *Monday, 26th of February*, please return the RSVP slip to us or contact us by telephone below. We look forward to hearing from you soon. Directions to travel to the Assembly are overleaf.

Genetic Interest Group (c/o Miss Buddug Williams)
Wales Gene Park, Medicentre,
Heath Park, Cardiff CF14 4UJ
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Contacting your AMs

Please write to or contact your Assembly Members and ask them to join us on the 1st of March so that they can learn more and help to improve health services and treatment of FH. It is important that we have support from Assembly Members to improve services for FH as they are elected representatives who can influence and decide health policy and the provision of health services.

Below is a letter template and additional points that you may wish to include which relate to FH. However, please add your own personal comments. Overleaf is a list of who are your Assembly Members. If you would like further information or assistance, please contact Buddug Williams on 029 20 68 21 40

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Your address
Date

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

Dear [Name] AM

- Please describe your family background relating to FH [e.g. "I have a condition called familial hypercholesterolaemia (FH) which is inherited high cholesterol". Do any relatives have FH? How has this affected them?]
- Modern medications for FH and lifestyle information about diet and exercise are very effective in prevention of heart disease [e.g. please describe your own situation – have your cholesterol levels decreased, or have you stopped smoking since you have been attending the specialist lipid clinic?]
- There is no established health service to offer information, advice and diagnosis to people with and at risk of FH in Wales. However, it is important that relatives and other families are offered an opportunity to be identified so they might receive treatment and advice. [e.g. How might such consequences affect you and your family?]
- Invite them to the FH awareness day on Thursday the 1st of March at the National Assembly in Cardiff Bay from 12.30pm in Committee Room 22. They will have the opportunity to find out more about FH and also have a chance to meet with you and the FH special interest group. [e.g. This is an opportunity for us to high-light the importance of care and treatment for people with FH]

Yours sincerely,

[Your Name]
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Additional facts about FH.

- In some families high cholesterol is inherited and passed on from parent to child. This is known as Familial Hypercholesterolaemia (FH).
- FH causes heart disease in young men and women.
- FH is common. It affects 1 in 500 people in the UK. In Wales there are thought to be 6000 individuals with FH but 4,800 remain undiagnosed and untreated.
- Heart disease in people with FH can readily be prevented by modern and inexpensive treatments (tablets and lifestyle).
- The NHS in Wales needs to set up a coordinated team of specialist nurses to plug the gap in diagnosis and treatment for families with FH.

How to contact your Assembly Members (AMs)

Everyone has a CONSTITUENCY AM. He or She represents your area. In addition are REGIONAL AMs – these are other AMs who represent a region which will include your area and there are four Regional AMs for every region. Therefore, you can contact up to five AMs.

Below is a list of Assembly Members. Find your constituency (where you live) on 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.

If you have any comments or are unsure of your area, contact Buddug Williams on:
029 20 682 140

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The Parties are: Conservative - C, Independent - I, Plaid Cymru - PC, Labour – Lab, Lib Dem - LD.

Mid and West Wales	CONSTITUENCY AMs:	REGIONAL AMs:
Brecon & Radnorshire	Kirsty Williams (LD)	Lisa Francis (Con)
Carmarthen East & Dinefwr	Rhodri Glyn Thomas (PC)	Helen Mary Jones (PC)
Carmarthen West & S Pembro	Christine Gwyther (Lab)	Glyn Davies (Con)
Ceredigion	Elin Jones (P)	Nick Bourne (Con)
Llanelli	Catherine Thomas (Lab)	
Meirionnydd	Lord Elis-Thomas (P)	
Montgomeryshire	Mick Bates (LD)	
Preseli / Pembrokeshire	Tamsin Dunwoody-Kneafsey (Lab)	

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South Wales West

Aberavon	Brian Gibbons (Lab)	Alun Cairns (Con)
Bridgend	Carwyn Jones (Lab)	Peter Black (LD)
Gower	Edwina Hart (Lab)	Janet Davies (PC)
Neath	Gwenda Thomas (Lab)	Dai Lloyd (PC)
Ogmore	Janice Gregory (Lab)	
Swansea East	Val Lloyd (Lab)	
Swansea West	Andrew Davies (Lab)	

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South Wales Central

Cardiff Central	Jenny Randerson (LD)	David Melding (Con)
Cardiff North	Sue Essex (Lab)	Jonathon Morgan (Con)
Cardiff South & Penarth	Lorraine Barrett (Lab)	Leanne Wood (PC)
Cardiff West	Rhodri Morgan (Lab)	Owen John Thomas(PC)
Cynon Valley	Christine Chapman (Lab)	
Pontypridd	Jane Davidson (Lab)	
Rhondda	Leighton Andrews (Lab)	
Vale of Glamorgan	Jane Hutt (Lab)	

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South Wales East

Blaenau Gwent	Trish Law (Ind)	William Graham (Con)
Caerphilly	Jeffrey Cuthbert (Lab)	Laura Anne Jones (Con)
Islwyn	(Irene James) (Lab)	Mike German (LD)
Merthyr Tydfil & Rhymney	Huw Lewis (Lab)	Jocelyn Davies (P)
Monmouth	David Davies (Cons)	
Newport East	John Griffiths (Lab)	
Newport West	Rosemary Butler (Lab)	
Torfaen	Lynne Neagle (Lab)	

**Wales Familial Hypercholesterolaemia (FH) Forum
Awareness Day at the National Assembly for Wales**
Crickhowell House, National Assembly for Wales,
Pierhead St, Cardiff Bay CF99 1NA
Thursday 1st of March 2007, 12.30pm Committee Room 22

By car From the West: Leave M4 at junction 33 & follow signs for Cardiff Bay / Techniquest 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.

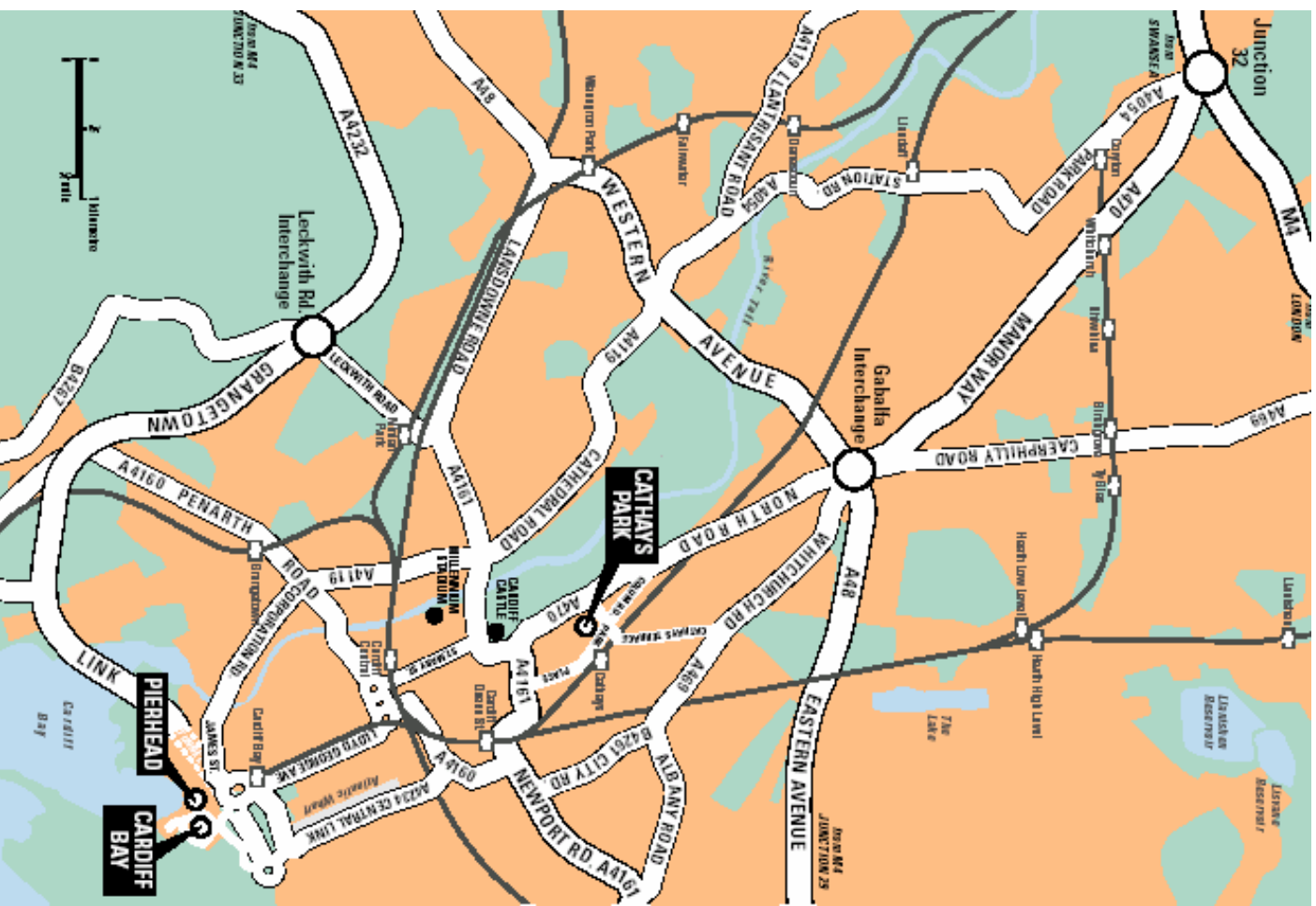
By bus: Cardiff Buses numbers 7, 8 & 9 run past the Assembly building or the Wales Millennium Centre (next door).

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 on Pierhead St., which is closest to

Crickhowell House a car park is also at the Red Dragon Centre (UCI cinema), Hemingway Rd

a car park is also at Stuart St (opposite Techniquest) another car park is available at Havannah St



Reply Slip

Wales Familial Hypercholesterolaemia (FH) Forum

Awareness Day at the National Assembly for Wales

**Crickhowell House, National Assembly for Wales,
Pierhead St, Cardiff Bay**

Thursday 1st of March 2007, 12.30pm Committee Room 22

Yes, I will be attending this event.

Your name and name of any others attending the event:

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Please send this reply slip to the address below, or contact us by email, fax or telephone (office hours).

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