

Newsletter

News from the Network Team

Welcome to our first newsletter of 2019 containing project updates, inspiring patient stories and an opportunity to introduce you to some new members of our team. We are delighted to welcome Cat McElvaney (Interim Network Manager) and Morwenna Bugg (Network Support Manager) to the Network Team.

We are sad to say goodbye to Caitlin Moss, who has worked as the Network Manager since the Networks initiation in April 2016. Caitlin has been appointed substantively to the role of Deputy Divisional Director for Women's and Children's Services in University Hospitals Bristol, following a short-notice secondment in October 2018. Caitlin has loved working with all of the Network's stakeholders across the region, and being part of the team from day one of the network being set-up. She is incredibly proud of what has been collectively achieved, and has mixed emotions about moving on. In her new role, Caitlin will remain responsible for children's networks from a University Hospitals Bristol perspective, so will continue to be involved in and supportive of the Network moving forward. We would like to thank Caitlin for all her hard work, determination and commitment, which undoubtedly has been a major factor in the success of this Network. A process for the substantive recruitment to the Network Manager role will launch in the coming weeks, so watch this space!

2019 promises to be a busy year for us with an ambitious work programme. However, progress would not be possible without the fantastic collaboration of colleagues. This is exemplified by the truly excellent work from our Dental Team led by Mick Allen, Consultant in Special Care Dentistry and Rosemary Power, Consultant in Paediatric Dentistry. See page 2 for more details.

Finally, later this year NHS England's Quality Surveillance Team will conduct a programme of Peer Review visits to all Level 1 and Level 2 centres in the UK. Our Peer Review Visit is scheduled for the 10th-12th of June 2019. An assessment will be made against the published NHS England Standards for Congenital Heart Disease. It is clear that an assessment of CHD Networks, across the UK, will be an important part of these visits. We can be rightly proud of the collaboration and work and we have completed to date.

Meet Morwenna, Network Support Manager



Morwenna recently joined the Network Team and will be a great support in helping the network to deliver its ambitious work programme. Previously Morwenna worked at NHS Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group after studying nutrition at university.

Key contacts

Clinical Director: Dr Andrew Tometzki

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Lead Nurse: Sheena Vernon

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Interim Network Manager: Cat McElvaney

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Lead Psychologist: Ness Garratt

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Support Manager: Morwenna Bugg

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Top Tips to Protect Your Teeth and Your Heart



Congenital heart disease and good dental health have an important relationship. Tooth decay and gum disease are preventable and the greatest risk of endocarditis comes if someone does not clean their teeth frequently.

Recommended brushing in adults, young people and children:

1. Use a **fluoride containing toothpaste**. NHS England (and dentists) recommend;
 - Children under 3; Smear of toothpaste containing at least 1,000ppm fluoride.
 - Children 3-6 A pea-sized piece of toothpaste containing more than 1,000ppm fluoride.
 - Over 6 and adults use toothpaste with at least 1350-1500ppm fluoride.
2. **Brush twice a day** carefully using circular motions ensuring the brush touches the teeth and the gums around them. Do this for two minutes.
3. Spit out the toothpaste but **do not rinse your mouth with water**. If you rinse you are washing the protection away!
4. Adults in particular, but children and young people with adult teeth should **clean between their teeth once a day** with either **dental floss** or an **interdental brush**.
5. If you notice some bleeding of your gum remember to clean that area more thoroughly as described above. You will not damage the gum this way, but if you brush the area less it will become damaged by the germs that are causing the bleeding.
6. **See a dentist** for a screening visit and talk about your own particular dental risks and needs. If you clean your teeth well, eat a healthy diet and keep sugar hits to mealtimes you will be doing really well!
7. Sometimes the dentist will prescribe a higher concentration fluoride toothpaste if you or your child are at higher risk of tooth decay.

Check out this website and free brushing app!

www.brushdj.com



We've got this! - meeting the CHD Dentistry Standards

There is great work underway in the Network to meet the standards for dental care for patients with CHD.

A working group, led by Mick Allen, a Consultant in Special Care Dentistry in Aneurin Bevan University Health Board and Rosemary Power, Consultant in Paediatric Dentistry at UH Bristol, has been set up to work towards achieving the CHD dental standards. Together this group provide a wide body of experience in dental care services for adults and children with congenital heart disease.

Achievements to date!

- ✓ **Draft dental care pathways** for adult and paediatric patients have been developed. These pathways will provide a framework with which commissioners and practitioners can develop services within primary and secondary care settings.
- ✓ **Resources** have been developed for patients, their families, dental and medical practitioners and cardiology teams to access so that the best, and most up-to-date advice is available to all involved within the Network and wider care.



My ACHD Story

By Julie-Ann Park, from Cardiff

I was diagnosed with congenital heart disease at 4 days old. I had truncus arteriosus. I've had 3 operations: 7 days old in 1986 at Southampton Children's Hospital; planned surgery in 2001 at Bristol Royal Hospital for Children aged 14; and emergency surgery in 2017 at the BRI heart institute aged almost 31.



Undoubtedly June 2017 was one of the hardest times of my life. I was admitted to hospital in Cardiff after feeling unwell for some time before transferring to Bristol for emergency surgery. I was in hospital for over 5 weeks. My parents knew what to expect but having to prepare my husband for what he would see and what would happen was draining for both of us. Having to decide if I was going to have a tissue or a mechanical aortic valve was difficult. This would affect the rest of my life. I opted for mechanical. So with a bit of luck - it should last for life.

What I struggled with after the surgery was how ill I felt. I was in intensive care. I was very sick, had no energy and experienced a lot of pain. I had a Chylothorax Leak so my chest drains stayed in for 12 days instead of 2. When they came out and I was allowed to go home on a very strict low fat - Chyle leak diet until my 8 week check-up.

The hospital encouraged me to mobilize. I purchased a fitbit to make sure that I was doing a few extra steps each day!! This helped to push me a little bit further.

I got into a routine of sorting my medication out each Sunday for the following week. Getting to grips with Warfarin and learning what food I could eat and in what quantities so that it didn't affect my INR. I purchased a coaguheck machine with the help of The Somerville Foundation (<http://www.thesf.org.uk/>). This was the best thing I have ever done. My GP agreed to prescribe testing strips so I can check my own INR wherever I am, whenever I want, which gives me peace of mind that everything is ok.

Cardiac Rehabilitation at the hospital and then with a cardiac instructor in my local gym helped get me back to physical activity, return to the gym and eventually back to work. It gave me a safe and controlled environment in which to do it.

A massive thank you to my consultant Dr Szantho, my Surgeons Mr Parry and Mr Coupan. I owe them my life. They did a fantastic job getting me through a very difficult time. The kindness the cardiac nurses Sarah Finch and Bethan Shiers have shown has been amazing. They do a fantastic job of putting you at ease. They have been more like friends and I know that I can talk to them about anything.

When I wrote this 13 months after my surgery I was still recovering but getting on with my life and feeling much more positive about my future. I really hope that sharing my story helps show people that there is life for an ACHD Patient before and after surgery.

Dr Dirk Wilson is crowned Health Hero



Dr Wilson is the clinical lead for the Paediatric Cardiology service in Cardiff and sits on the Network Board. Recently he received a well-deserved nomination from the ACHD nurses and was crowned Health Hero in Cardiff in December.

“Dr Wilson goes above and beyond to support his patients and their families. He is instrumental in ensuring that patients are treated with respect and dignity and he holds an in-depth knowledge of the patients we look after. He will always go the extra mile to ensure patients and their families feel safe and supported. His patients always comment on his approachable, friendly manner and will often ask specifically to see him in clinic! He is extremely encouraging of his colleagues and specialist nurses; ensuring they feel valued and supportive of new developments and ideas to enable service improvement.”

Read the full story here:

<http://www.cardiffandvaleuhb.wales.nhs.uk/news/49994>



Meet the Paediatric Cardiac Nurse Specialist Teams

Who are we?

The Network has two Cardiac Nurse Specialist (CNS) Teams, one based at Bristol Royal Hospital for Children (BRHC), supporting families in the South West Peninsula and one at Noah's Ark Children's Hospital for Wales based in Cardiff, supporting families in South West Wales.



Both teams are comprised of experienced nurses who work as part of the wider multidisciplinary team to provide ongoing information, advice and support to children and their families with a congenital/acquired heart condition. Both teams work closely together to ensure seamless care for Welsh families who come to Bristol for surgery and catheter procedures.

How to contact the Bristol Children's CNS team

Phone: 0117 342 8286 or 0117 342 8578

Email: cardiacnurses@uhbristol.nhs.uk

How to contact the Cardiff Children's CNS team

Claire Logan - Cardiff & Vale and Rhondda Valleys – 02920 745184

Wendy Williams/ Jenni Stirling - Bridgend/Swansea and West Wales- 02920 744653

Karina Parsons-Simmonds - Gwent/ Merthyr 02920 745524

Ann Jermyn - Transitional Nurse Specialist 13-19 yrs 02920 748046

Alison Pearce- Fetal Nurse Specialist 02921 841746

When will you meet us?

When you are pregnant:



The Bristol and Cardiff CNS team supports the fetal service and are available to expectant parents at the time of diagnosis to answer questions or queries and to support care planning for birth and treatment that may be required following this.

When you are staying in hospital:

The Bristol CNS team operate an on-service system throughout Bristol Royal Hospital for Children Mon-Fri to ensure that all cardiac patients have access to the team during their inpatient stay. The named nurse specialists in Cardiff offer support for inpatients on Pelican Ward and see their patients on a daily basis. This service is also available to patients on the neonatal unit in both Cardiff and Bristol.

At your outpatient clinic appointments:



The CNS's are available to patients and families during routine outpatient appointments as well as being supporting and preparing families for upcoming inpatient stays.

Home visits (Cardiff):

In Wales home visits are offered for pre-op preparation together with the Hospital Play Specialist if needed. Telephone preparation for Cardiac Catheterisation is offered.



At transition clinic appointments:

The purpose of transition clinics is to ensure smooth transition of care to adult services. In Bristol and Cardiff these clinics are supported by the CNS team. In Cardiff home visits are also carried out when required.

THE FUTURE!

Both teams have the same ultimate goal to provide an expert, accessible service to all patients and their families no matter where they live in the network catchment area.

If you are interested in finding out more about the role of a Cardiac Link Nurse then please contact the team



The Experts' View: Ten Exercise Tips for the ACHD Patient

From the Somerville Foundation newsletter: https://thesf.org.uk/wp-content/uploads/2018/12/GUCH_Issue-91.pdf

1 **Exercise really is good for you!** If you are a 'couch potato' your skeletal muscles and breathing muscles become much less efficient. This puts additional strain on your heart and lungs – keep yourself as fit as you can and you really will feel better!

2 Taking part in **regular exercise reduces the risk** of developing diabetes, brittle bones (osteoporosis), some cancers such as bowel cancer and breast cancer and helps treat high blood pressure.

3 **Exercise is a great social activity.** Find a form of exercise you enjoy. There is lots of evidence to show that regular exercise improves mood and reduces anxiety.

4 In general **aerobic exercise is best for the heart** (walking, running, cycling, swimming). Isometric exercise (such as lifting heavy weights) puts more strain on the heart and is better avoided or should be taken with caution.

5 If you are not sure how much exercise to do, or what is the best sort of exercise, **ask for an exercise prescription!** This is a specific prescription you can be given that will advise you exactly how much exercise to do, what is good for your heart and what is more of a problem.

6 You can still **exercise if you have joint or muscle problems.** However, get some advice from your GP or ask for referral to a local physiotherapist who can assess and advise.

7 The American College of Cardiology have suggested that **exercise activity should be discussed with you every time you see a clinician.** This recognises the importance of encouraging you to exercise regularly. It is also important to make sure that you are not doing anything that might put you at risk. If no one discusses exercise with you, then you should ask for advice from your nurse, your surgeon and your cardiologist!



8 There is a lot of information available for patients with congenital heart disease at the **online exercise resource** <https://chd.heartresearch.org.uk> this is designed for both children and adults with congenital heart disease.

9 There are some exercise techniques which can help **strengthen your lung muscles** and might **improve your breathing.** The physiotherapists at your local ACHD clinic should be able to advise you if this might be useful for you.

10 If you are exercising and you feel faint or get palpitations you should ease up and **discuss with your cardiologist.** If you faint during exercise, it is very important to let your cardiologist know. However, in general exercise is a very safe and effective way of improving your healthcare.

Article by:

Dr Graham Stuart, Consultant
Cardiologist, Bristol Congenital Heart Unit

Caroline Evans, Senior Cardiac
Physiotherapist, Bristol Heart Institute

Craig Williams, Professor and Director of
Children's Health and Exercise Research
Centre, University of Exeter



Introducing Dr M Cecilia Gonzalez Corcia

The Network would like to introduce one of the recently appointed Consultant Cardiologists, Dr M Cecilia Gonzalez Corcia specialising in Electrophysiology in Congenital Heart Disease.

Background and Training

Born in Buenos Aires, Argentina, Dr Gonzalez Corcia did her medical studies at the University of Buenos Aires, and trained as a paediatrician at The Children's Hospital of Buenos Aires "Hospital de Niños R. Gutierrez". She then pursued training in Paediatrics in Philadelphia, and continued with a fellowship in Paediatric Cardiology at Boston Children's Hospital. After finishing her subspecialist training in Paediatric Electrophysiology and Pacing, she moved with her family to Belgium where she developed the Paediatric Electrophysiology Program in Clinique St Luc, the Catholic University Hospital in Brussels from 2012 to 2017.



Interests / expertise / research in CHD

Dr Gonzalez Corcia has a clinical and research interest in arrhythmias, and was mentored for her PhD in Brugada syndrome in the young by Professor Pedro Brugada. Thus, she has a special interest in cardiac arrhythmias and inherited cardiac conditions including channelopathies. Her other main clinical interest is interventional electrophysiology in young children and in patients with congenital heart disease. She has published several scientific papers and is frequently invited for presentations to national or international scientific meetings.

Current role and experience

Dr Gonzalez Corcia has been recently appointed as Consultant Cardiologist in the Cardiac Centre at Bristol Royal Hospital for Children. Her position includes holding arrhythmia and pacemaker clinics for children with inherited cardiac conditions both in Bristol and Musgrove's Park Hospital in Taunton. She carries out interventional arrhythmia procedures in both children and adults including pacemaker and defibrillator implantations and ablations.

Interests outside of work

Dr Gonzalez Corcia has an incredibly supportive husband, and is the mother of 3 children: Santiago, Mateo and Maia-Sophia. All the family relocated to UK when she was offered the position, and are now enjoying their new Bristolian lives!

Finally, Dr Gonzalez Corcia is a hockey player and is hoping to find a team soon to go back to her favourite sport!

Contact details

cecilia.gonzalezcorcia@UHBristol.nhs.uk
0117 342 8852



Welcomes & Goodbyes

There are a number of changes in the clinical teams in Bristol Royal Hospital for Children to update you on;

Farewell and thank you to Dr Michael Yeong who has returned to Australia.

Welcome to Dr Ines Gomes who will be joining the team in Spring as a fetal cardiologist. She will be running the South Bristol clinic.

Welcome to Dr Sri Naryan who will be joining the team in the early summer as a cardiologist with an interest in imaging. He will be covering Dr Yeong's clinics in Barnstaple and Gloucester.

Welcome to Dr Francisco Gonzalez who will be covering clinics in Truro and Plymouth (previously provided by Dr Alison Hayes).

Further changes will be taking place over the year as various senior colleagues finalise their retirement plans, including Dr Graham Stuart (Truro, adult clinics), Dr Rob Martin (who covers Exeter clinics) and Dr Alison Hayes (whose paediatric peripheral clinics are being taken over by Dr Gonzalez).



Do you or a member of your family have a congenital heart condition?

Would you like to help make a difference for patients and families?

Become a patient representative for the network!

Patient involvement is very important to the network. We exist to serve our patients and their families/carers. The role of the patient representative has been developed to ensure that the views of patients, carers and families are taken into consideration when developing services, making decisions or undertaking activities.

We would like to invite current or past users of NHS services related to congenital heart disease (as a patient, parent or carer) or representatives of a patient support group to become patient representatives for the Network.

Being a Patient Representative

By Becky Nash, CHD Network Patient Representative

My name's Becky Nash, I'm one of the patient representatives on the CHD Network for the South Wales & South West. I'm a 32 year old mum of two and a registered nurse working in palliative care. I have had two open heart operations; one at aged 10, then again at aged 29. A little of my story is on the network website.

I was at a routine follow up appointment when Sheena Vernon, the Networks lead nurse, asked if I'd like to be involved. I jumped at the chance. The main reason being an enthusiasm to be able to help anybody else having to go through heart surgery, or indeed living with a congenital heart defect. It had been such a huge and life changing experience for my family and I was extremely keen to be able to support others in whatever small way I could. It felt like a real positive, to come out of such an unpleasant experience. I felt extremely motivated leaving that appointment!

In the months that have followed, I have found myself attending board meetings all over the South West and South Wales, expenses of which have been covered by the Network. It's been a privilege to be, and continue to be involved. It's particularly exciting as we work together with Sheena, the Lead Nurse, to develop the patient representative role. We met in November as a small group, to discuss a job description, terms of reference and timescales of involvement. Over the past six months or so we have really tried to be involved, so that the patient representative role is engaging and productive.

The aim, as I view it, is to work together as a Network, to ensure the very best care for congenital heart patients across our region. I think the board agree that it is so vital to have the voices of real patients and families in order to achieve this goal.



Becky Nash, CHD Network Patient Representative

What do our patient representatives do?

- Offer ideas and opinions which reflect the voice of patients, carers and their families.
- Feedback to teams on their personal experience.
- Support improvement projects
- Review content such as the website and other public facing information.
- Participate in audits and surveys
- Attend board meetings.

**To find out more information or to apply to become a patient representative please contact Sheena, the Network Lead Nurse
sheena.vernon@uhbristol.nhs.uk**

Network Dates for your Diary!

Key Network Meetings;

- 21st March:** Clinical governance group
1st May: Network Board meeting
9th July: Stakeholder day

Network Training and Education events

- 2nd April:** Peer review training
18th March: Adult CHD education day
21st March: PEC study day

For more information please visit our training and education page on our website
www.swschd.co.uk/en/page/training-and-education



Preparing for Cardiac Surgery



Psychological Health Services – Lifespan Cardiac Psychology Team: Vanessa Garratt, Michelle O’Keeffe, Nell Ellison, Joanna Latham

This is the part of an article written by the Psychological Health Services- Lifespan Cardiac Psychology to help adults, parents and children prepare for cardiac surgery. The full article can be accessed on our website:

www.swswchd.co.uk/en/page/getting-support-cardiac-surgery

As a team of four Cardiac Clinical Psychologists we offer support to children, young people and adults who feel a mixture of hope and relief to be offered surgery for a cardiac condition, but may also have questions and worries about what surgery might be like. Cardiac surgery is a positive but significant event for a person and their family to go through so it is not surprising that people might feel a bit anxious before and afterwards. Anxiety is a normal experience in the context of having surgery. This article explores some of the concerns people may have about cardiac surgery and provides some ideas for how to manage these concerns

Children and Young People sometimes will be worried about the impact of cardiac surgery on their life; missing school whilst in hospital, being away from their family members, and not being able to spend as much time with their friends during their admission.

Parents often are worried about how to tell their child about their heart condition, what will happen on the day, the risks of surgery, and how to cope through this tough time. It is also common for parents to wonder about the recovery process and the duration of the hospital stay

Adults As people get older they may have different worries about cardiac surgery to when they were younger. Everyone has their own unique experience of living with congenital heart disease but it may be helpful for people to know that they are not alone in some of their fears about surgery and the recovery process

Things that might help; We know there are things that might help to prepare you and/or your child prepare for cardiac surgery. If you would like to find out more please visit our website on www.swswchd.co.uk/en/page/getting-support-cardiac-surgery

Where can I get support?



It can be hard to know what you need and where to find this.

There are a number of national and local resources on our website that might suit your needs or answer questions that you have.

We also know that different types of support will work for different people. You may prefer to read information and try out strategies at home, see someone locally or access specialist cardiac support via the telephone or in person in Bristol.

By using the resources on our website you can find out what you need and where you can go to find it.

Find out more by going to;

www.swswchd.co.uk/en/page/getting-support



Obstetric Cardiology Service



Established in 1998, the obstetric cardiology service at University Hospitals Bristol has been running for 20 years. Initially only a few patients were seen once a month in the BRI and now the clinic runs all day twice a month and is still growing!

Women are supported from pre-pregnancy counselling right through pregnancy, delivery and the post-partum period. At each appointment the prospective mum will see the cardiologist, obstetrician (and anaesthetist if need be) and have all scans such as ECG and echo done at the same time. This 'one-stop clinic' model of care is recommended by the Royal College of Obstetricians and Gynaecologists and European Society of Cardiology as being the best way to manage pregnant women with heart disease. Baby scans can be done and fetal echoes are arranged so that the baby's heart can be checked by a paediatric cardiologist.

A personalised delivery plan is made for and discussed with every woman to try to make the birth of her baby as natural as possible, but within the constraints of her cardiac condition, so that she stays safe. The majority of women with cardiac conditions are able to deliver normally, but may have restrictions on the amount of pushing that they are able to do. Epidurals reduce cardiac stress associated with pain and control blood pressure, so are often advised in labour. People are often surprised by this as they may have been told that a caesarean section is necessary. This is not the case, as caesareans often cause more stress on the heart.

Though most of our women have congenital heart disease, we also see women with acquired heart disease, such as heart rhythm problems, and inherited cardiac conditions, such as Marfan's syndrome.

The obstetricians are Dr Jo Trinder, Dr Aarthi Mohan and Dr Louise Ashelby, the cardiologist is Dr Stephanie Curtis and the anaesthetists are Dr Mark Scrutton, Dr Issie Gardiner and Dr Claire Dowse. The lead midwife is Mrs Tracey Bungay.

Each clinic starts with a multi-disciplinary team meeting discussion of upcoming delivery plans and all high risk pregnant patients throughout the region.



Want to know more?

Visit the Somerville foundation website: <https://thesf.org.uk/achd-pregnancy/> and download the pregnancy leaflet.

It includes information on:

- Planning pregnancy
- Discussing plans for pregnancy with your cardiologist and obstetrician
- The baby's outcome
- Questions to take to clinic
- Caring for your baby
- Caring for yourself



And finally...

We cannot have a winter newsletter without mentioning the fantastic Christmas 2018 parties hosted for children with CHD and their families! These events are held to celebrate the courage shown by the children and their families as they navigate through their CHD journey. It's also a great opportunity for families who often meet under very stressful circumstance to catch up and have some fun.

Childrens Cardiac Christmas Party

With support from the Grand Appeal and the Bristol Marriott Royal Hotel, the nursing staff on Dolphin Ward at Bristol Royal Hospital for Children hosted their annual Christmas party on Sunday 16th December.



It was lovely to see so many amazing children and their families (almost 300 in total!) and a fantastic afternoon was had by everyone. There was dancing, party games, face painting, fun tattoos and off course a much loved visit to see Santa!

Heart Families South West Christmas Party

On Sunday 2nd December thirty eight Heart Families came together at Bristol Zoo Gardens for Heart Families South West annual Christmas party. The day included a Face Painter, a festive Photo booth, a buffet lunch, a raffle to raise funds for The Wallace and Gromit Grand Appeal and a visit from Santa and his elves.



The party is a great opportunity for Heart Families to meet others that understand the journey their children are on and to have lots of fun.

The day was a huge success and it was lovely to see families that have gone through so much spend special family time together. Huge thanks goes to The Wallace and Gromit Grand Appeal for funding the party and Apel Elain for funding the Photo booth and the balloons.

Want to know more?

The network website is for patients, families and clinicians.

We have information on:

- Patient leaflets
- Getting support
- Hospitals & Clinicians across the network
- Patient stories
- Patient pathways
- Clinical information
- Network meetings & training events
- Research



Thank you for reading!

If you have any stories or ideas you would like to share for the next edition in **September**, please contact morwenna.bugg@uhbristol.nhs.uk

We welcome:

- Patient/family/staff/team stories
- Clinical news/updates
- Events
- Network related issues
- Anything else you think might be relevant!

The newsletter will be published twice a year. If you would like to sign up to our mailing list, please email Morwenna Bugg, Network Support Manager on the address above or you can sign-up on the home page of the network website: www.swswchd.co.uk