

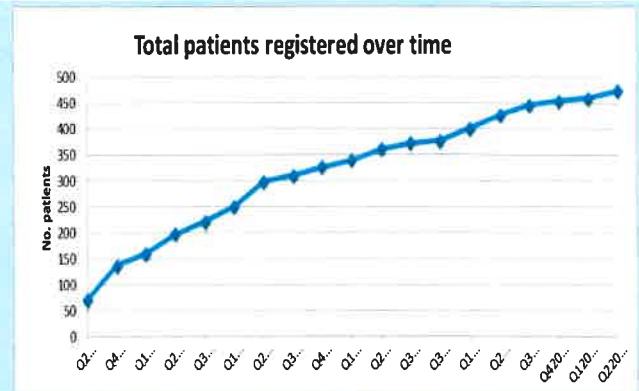
FH PAEDIATRIC REGISTER NEWSLETTER

THE NEWSLETTER FOR CLINICIANS WHO ARE REGISTERED WITH THE FAMILIAL HYPERCHOLESTEROLAEMIA
PAEDIATRIC REGISTER WEBSITE

LATEST FIGURES

We now have **474 children enrolled in the register**. Since the introduction of the automated annual update reminder, we continue to see an increase in follow-up data entered. We now have **656 annual updates in the system**.

Do remember that clinicians can continue to enter patient data even once the patient turns 18 years of age, so long as they remain under that clinician's care.



GDPR is coming on 25th May 2018!

What?

GDPR stands for the 'General Data Protection Regulation' – it is an EU-wide harmonisation of data protection law, which aims to give stronger rights to data subjects and protect them if their data will be exported outside the EU. It puts more responsibility on organisations holding *personal data* (any data which could identify a person – this includes coded or pseudonymised data), to show that they are: **keeping it as secure as possible; only hold information they need; only holding it for as long as they need to.**

There will be much higher fines for those found to be in breach of GDPR than the current UK Data Protection Act.

When? GDPR becomes effective on **May 25th 2018.**

What difference will it make?

Many of the rights of data subjects are the same as they were under the Data Protection Act but GDPR gives new rights to data subjects. Under GDPR, 8 new rights will be given to data subjects. We are reviewing the impact this will have on the Register and will be in touch with an update in the coming weeks.

New right	Explanation
The right to be informed	To be told what data is held and why, how long the data will be kept for and who it will be shared with – 'transparency'.
The right of access	To have access to data held free of charge.
The right to rectification	To be able to correct incorrect or incomplete information.
The right to erasure	To request that data held about them be deleted 'the right to be forgotten'.
The right to restrict processing	To request that data is not used for certain purposes even where it still is allowed to be stored.
The right to data portability	To readily remove their data and transfer it elsewhere e.g. another research project, or care provider.
The right to object	To the processing of data already collected or to being contacted in relation to the project or for any other reason.
Rights in relation to automated decision making and profiling	To be able to oppose to decisions being made using automated decision-making based on data held

GDPR—future newsletters and email communication from us—we need your consent!



GDPR law also dictates that we are required to ask for your consent in order to be able to send you further newsletters, updates, information about training and workshops related to Paediatric Familial Hypercholesterolemia.

Therefore we will soon send you an email requesting that you confirm that you are happy to receive this information from us after 25th May 2018. You will be required to explicitly opt-in to confirm that you are happy to be contacted by us in the future.

Look out for this email which will be sent by Maggie Heinrich (MaggieHeinrich@phassociates.com) in the coming days. Please respond to it as soon as you can. If you have any questions about this, please contact fh@rcplondon.ac.uk

Paediatric FH Meeting King's Fund April 18th – Prof Steve Humphries and Dr Uma Ramaswami report



The meeting was a great success and well attended, with over 80 registrants including several Paediatricians and even 1-2 commissioners! For those of you who couldn't attend, the BHF have filmed all the presentations and will be putting them on the internet sometime soon, when we will of course send you details.

Dr Huon Gray made some opening remarks, where he emphasised the amazing progress that has been made over the last 5 years in getting FH onto the Health Care agenda. Particularly welcome is the fact that from October this year, when the DNA diagnostic laboratory services in England will be re-organised into seven hubs, the costs for DNA testing for FH will be covered by NHS England as part of the “core” DNA tests portfolio.

The 2017 update of the NICE FH guideline has made only minor amendments to the child-care pathway, and has re-enforced the utility of DNA testing, and consideration of statin therapy by the age of 10 years. Taken together with the successful roll-out of cascade testing across the UK, this will mean that there will be a considerable increase over the next 5 years in the number of children with FH that will be detected and need management.

Three key issues came out of the presentations and workshops. The first was that we need to increase awareness of the importance of early statin treatment in children with FH, both to clinicians and to parents. Secondly we need to identify more clinicians to take on paediatric FH service across the country, as there are still many areas with little or no current services. Finally, probably the most important thing we can do to improve the availability of paediatric services for children with FH would be to encourage (and fund!) the training of many more FH-Paediatric Nurses. These could be based in secondary care settings, with outreach to primary care, and, working under the supervision of a clinic doctor, could effectively manage much of the patient care pathway.

So while acknowledging that there is still much to do, the meeting finished on a very positive note, with the view that with continued help and support from BHF and HEARTUK, we should be able to continue to improve the identification of children with FH and the services that they can be offered.

