

FH PAEDIATRIC REGISTER NEWSLETTER

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

Dear Colleagues,

Welcome to the second Familial Hypercholesterolaemia Paediatric Register newsletter. Since the last newsletter in March 2013, we have sent out surveys to all clinicians who have enrolled on the FH register website (which can be accessed below) to determine how many patients are currently diagnosed, but not registered. We have also been investigating barriers to the registration process, and encouraging you to tell us how we can support you in this. Collecting this information is important, as we want to ensure that the registration process is as smooth as possible. Finally, we will be attending the Royal College of Paediatrics and Child Health conference in Birmingham in April 2014; you'll find the details overleaf. We hope to see you there!



Prof. Steve Humphries
Steering Group Chair

REMEMBER - WE ARE OFFERING FREE DNA TESTING

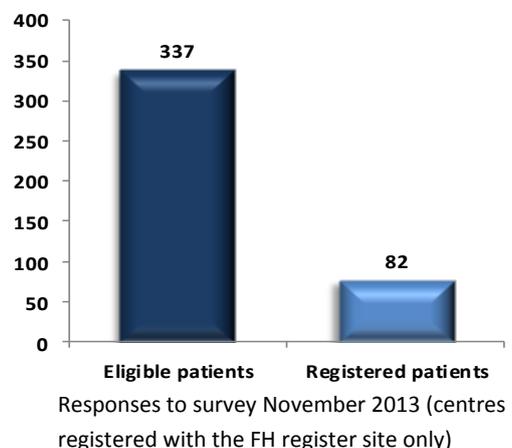


In our last newsletter we were pleased to announce that that we are able to offer clinicians who enter data onto the FH Children's Register the possibility of sending blood samples for genetic testing to the British Heart Foundation funded Cardiovascular Genetics Research Laboratory at UCL. We are happy to provide this for any registered child with a family mutation that has not been identified. If you would be interested in sending samples, please contact us at fh@rcplondon.ac.uk and ask for a pro-forma, DNA consent form and instructions about how to collect and send the sample.

ARE ALL YOUR PAEDIATRIC FH PATIENTS REGISTERED?

In our last newsletter, we updated you with information about how many patients were registered on the FH paediatric register. Since then, **the number of children registered has increased from 33 to 137 full registrations and 19 incomplete registrations!** To keep this good work moving forward, we have contacted all clinicians who have enrolled with the FH paediatric register website to find out how many eligible patients there are and how many of those are registered. As mentioned above, we have also been asking about barriers you face in the registration process and ways in which we can support you. You can find more about this overleaf.

So far, almost 40% of the enrolled clinicians we have contacted have sent us information about the number of patients eligible for registration and the number who are currently registered. This information can be seen in the chart to the right. If you have received the survey, we would be grateful if you could fill it in. Don't forget to pass it on to your colleagues!



SUPPORT NEEDED FOR REGISTRATION OF FH PAEDIATRIC PATIENTS

In the survey we recently sent out, many of you told us that time constraints were an issue, particularly when obtaining consent. One way to overcome this is to give patients or parents consent forms to take home and send back. However, some of you have told us that there is a problem with patients returning forms. If this is an issue for you, we are able to offer stamps to go out with pre-addressed envelopes, which may encourage patients to return their consent forms. Please contact us if this would be helpful for you.

A few of you also told us that it is sometimes difficult to obtain consent from patients or their parents. We hope that the information provided on our website (details about this are below) might help explain the importance of the register in lay terms and encourage patients or parents to consent.

In understanding the difficulties in the registration process faced by clinicians we can work together to develop solutions. If you haven't already told us about the difficulties you have faced, please let us know. You can contact the Project Manager at fh@rcplondon.ac.uk.

ARE YOU PART OF A NETWORK?

We know that some clinics will have very few paediatric patients diagnosed with FH. As such, we anticipate that clinical research will require a collaborative network of sites. The register will provide a means of identifying sites that might be prepared to participate in such a network. If you would be interested in joining one of our networks, please get in touch at fh@rcplondon.ac.uk.

CONFERENCES AND SEMINARS

We will be attending the RCPCH conference on the 10th April 2014 to run a workshop session between 11:30am and 1pm. The session will be led by **Dr Albert Wiegman**, paediatric cardiologist at the Academic Medical Center, Amsterdam, who will be presenting the Dutch model of Paediatric Heterozygous FH - management and follow up. There will also be talks from **Dr Peter Dale** (Royal Gwent Hospital, Wales), **Dr Uma Ramaswami** and **Professor Steve Humphries**, covering FH patho physiology and genetics, NICE guidelines and UK Paediatric FH Register data, cascade screening (the Welsh experience) and a brief update on newer treatments and Commissioning in England.

There will also be an opportunity to ask our experts questions. We are keen to promote the importance of the register for research in this field and to discuss the clinical management of children with FH. As such, Professor Steve Humphries (Lead) and Dr Uma Ramaswami (Clinical Lead) are available to attend local or regional meetings. For more information about this, please contact the project manager at fh@rcplondon.ac.uk.

FH REGISTER PROMOTION FOR PARENTS

We have put together some information about the register for parents with children who have been diagnosed with FH. This information may be helpful for clinicians who are having trouble obtaining consent from parents of patients. If you would like to use this information when speaking to patients, please visit our website at the address below, and click on 'Information for parents and patients'.