

CLDF Pro News April: Support through COVID-19 & Research Grant Update

Welcome to Pro News - CLDF's newsletter for healthcare professionals and researchers

Introduction and thank you

The devastating effects of the COVID-19 pandemic have been felt across the world. Many of you reading this will be closer to the impact of the virus than anyone else. Therefore, Children's Liver Disease Foundation would like to start April 2020's Pro News by thanking all those working in the NHS, whatever your profession. Your dedication during this time is inspirational and we know many of the families, children and young people we support feel the same.

We are continuing to support those affected by childhood liver conditions during this time. The channels we use and activities we are undertaking have changed but this a time of need for many families with children diagnosed with a chronic liver condition, have undergone transplants and are immunosuppressed.

We continue to be here for everyone affected by childhood liver condition. This includes supporting children, young people, families, healthcare professionals and researchers.

What has changed?

- We are continuing to provide support by phone, email and queries through our website
- We are developing ongoing tailored COVID-19 information and advice through statements, updates, blogs, digital catch ups and case studies.
- We are unable to attend hospital clinics
- We are unable to hold or attend events
- We are unable to process and post hard copies of information resources within the usual time scale. We advise that people download PDFs from our website page and view online information. Where hard copies are essential, or you have specific request we may be able to support shipping of small orders. If you complete the online order form a member of staff will be in touch to advise of how this will be processed. Please contact Harpreet (Information & Research Hub Manager) to enquire by calling 0121 212 6029, by email at irhm@childliverdisease.org or by completing the online order form
- The 2020 CLDF £10,00 research grant round has been cancelled and we are unable to accept applications at this time.

COVID-19 guidance and blogs

CLDF have developed a section on the website for all coronavirus (COVID-19) information. This is regularly updated as and when new information is received. You can view this here.

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Research

Due to the challenges caused by COVID-19 the CLDF 2020 £10,000 research grant round has been cancelled and we will no longer be accepting applications. This board decision has been taken with the support of our Scientific Committee Chair and Medical Director. The charity faces unprecedented financial challenges and we are also aware that many potential applicants and scientific committee members will not have the capacity to make applications or provide governance for the grant round. If you need further information please email research@childliverdisease.org. Further information is available on our website here.

Information

Ordering information resources

As we may be unable to ship resources within suitable timeframes please do access our information online. Information is available as PDFs which can downloaded and printed.

If it is essential that you receive hard copies of information please email irhm@childliverdisease.org or call 0121 212 6029 to discuss your needs with the Information & Research Hub Manager.

Living without a diagnosis

We recently promoted the review and redesign of the final support series leaflet called 'Living without a diagnosis'. To find out more about this publication visit our website page here.

Voice and Policy

Prescription charges information

There has been a rise in prescription charges and prescription prepayment certificates this year. Many young people are required to take several medications in order to manage their condition including anti-rejection medication. CLDF is a member of the Prescription Charges Coalition campaigning to end charges for all long-term conditions in England. View our recent article about the price increase and work of the coalition here. If there are any medical professionals who would like to support this campaign by providing a comment, please get in touch with Harpreet (Information & Research Hub Manager) at irhm@childliverdisease.org.

If you missed the Radio 4 documentary on this campaign led by a young person with a liver condition, Joanna, please listen back here.

We would like to take this opportunity to say thank you once again as well as stay safe and stay well.

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