



## Welcome...

to our Winter 2023 newsletter! We feature an update on our investment into Telemedicine for our FD community, as well as the upcoming Annual Quiz Night!

Please think of us when you are giving charitable donations. We depend on your generosity as it allows us to support our activities and FD families during the year. Please donate via:

<https://donorbox.org/fd-uk-donations>

We thank you for your support and for being part of our FD-UK community. Together we can make a difference! Wishing you a wonderful Winter! Gratefully, the FD-UK Committee.

## FD-UK Annual Quiz



Please take part in our 40<sup>th</sup> Annual FD-UK Quiz online! We really want to smash our previous £3,000 total so please register with your family/friends and join us on Sunday 5<sup>th</sup> March (Zoom opens 7.30pm, Quiz 8-10pm). A donation of £20 per household is suggested (but all amounts gratefully received!)

**To purchase tickets please visit:**

[www.fd-uk.org/events](http://www.fd-uk.org/events)

The superb Jo Grankin will again be testing our grey matter in what is sure to be a fabulous evening!

## FD Telemedicine consultations underway!

For many years we have worked with the New York Centre for FD, but until now their specialists were unable to give direct assistance to UK FD patients without them physically flying to New York. Having now launched telemedicine consultations we are delighted with the initial feedback (4 patients have now undertaken their first annual consultation).

Patients and their carers complete a medical questionnaire and undertake a few simple tests (blood samples, respiratory and bowel diagnostics) using the latest equipment. The NY FD Centre review the results and run an online face to face appointment to discuss results, raise any areas of concern, observe the patients on screen, and build a relationship in order to provide the best care. A full report with any recommendations is provided. These specialist FD medics are available during the year to discuss issues with the patients/families directly, as well as still being able to liaise with UK consultants to ensure the most appropriate approaches/treatments are provided. Having such expertise on hand is sure to prove invaluable as time goes by, and ultimately improve the patients' quality of life.

Natasha Lawrence (pictured right), the UK's first FD patient to go through this process said, "during the appointment they even wanted to meet my husband who I had talked about, and they really put me at ease. They are getting to know my detailed history and ongoing issues which helps make sure I get the most suitable treatments".



Importantly, all the equipment being used in the consultations, from medical to technological, such as the iPads for data transfer and the cost of the specialist consultations, is all funded by FD-UK. This brings clinical monitoring and healthcare assessments a remarkable leap forward, giving FD specialists the ability to be with patients in their homes, bringing the medical and patient communities much closer together. We are delighted, and without the donations we receive this could not have happened.

**Try our simple Text to Donate service!**

Along with the usual website donations page (<https://donorbox.org/fd-uk-donations>), this summer we launched a new text to donate service! We wanted to ensure that people could donate in a variety of ways (we even take contactless payments at events too!).

You can text to donate as follows (the amount simply gets deducted from your phone bill):

**Text FDUK5, FDUK10 or FDUK20 to 70085 to give £5, £10, or £20**

*\*texts will cost the donation amount chosen plus one standard network rate message and you'll be opting in to hearing from us further. If you do not want to hear from us after donating, please text FDUKNOINFO afterwards.*

**Eli gets creative, making a new FD design**



One of our FD patients, Eli (aged 14) has kindly put his love of art into designing a fabulous image for FD-UK, and we are pleased to announce that we will be using this image on, for example, greeting cards. We are proud of Eli and we're excited to share this with you.

We're always looking for talented young artists from our community so feel free to get creative and email in any pictures to our team ([reply@FD-UK.org](mailto:reply@FD-UK.org)) who will take a look and let you know what we think! We may even request your permission to use it!

**Jnetics screening results show FD gene as the most prevalent**



Jnetics is a registered charity dedicated to improving the prevention of Jewish genetic disorders in the UK. They focus on genetic conditions that, though not exclusively Jewish, are of particular relevance to people of Jewish ancestry. Jnetics recently informed us that FD is the most prevalent gene, they find in their screening. So, we aim to work even harder about building our awareness about FD and together to encouraging the community to get tested. It is estimated that everyone of Jewish ancestry has a 1 in 5 chance of carrying at least one of the main recessive Jewish genetic disorders that they test for. For more information about screening please go to their website: <https://www.jnetics.org/>

**FD-UK/Maccabi GB Southern Football League update**

We continue our association this season with the Maccabi GB Southern Football League. We are busy planning future events and further engaging with the Jewish football community to raise much needed awareness amongst 18-35 years olds, and to raise further funds. We will be at the Cyril Anekstein Cup final again, and perhaps one or two others. And we are featured on the MGBSFL social media channels showing match highlights.



**Donors & Fundraisers**

Thanks to all those who donated in memory of a loved one, or in celebration of other events.

Special thanks to:

- Dahlia Elton, who has been fundraising for her Birthday
- Jeff Kingsley, for raising donations for his 80<sup>th</sup> Birthday
- A significant medical Trust donation (anonymous)

We very much welcome anyone who wants to do celebrate milestones by fundraising for us, or to leave a lasting legacy gift, or to donate in memory of loved ones. *Please contact us if you wish to run a fundraising campaign, or simply use one of our donation services like Text to Donate, or Donorbox <https://donorbox.org/fd-uk-donations>*

**Don't forget to donate to FD-UK while shopping with Amazon Smile**

Don't forget to donate to FD-UK while you are shopping for Birthdays or essentials on Amazon please shop via amazonsmile and select FD-UK and they will donate 0.5% of your purchase, to us, it will not cost you anything! It is the gift that keeps on giving, thank you.



**Cook Book available: all proceeds to FD-UK**



With thanks to Mrs.Obermeister we have a few fabulous cook books, with 172 recipes still available for £12. Please email [reply@Fd-UK.org](mailto:reply@Fd-UK.org) if you would like a copy.

**FD-UK committee**

We are very grateful for all our committee members, who are all volunteers. We are so grateful for the time, support and skills all our committee members bring to the FD-UK committee. If you would like to be involved, please get in touch at: [reply@FD-UK.org](mailto:reply@FD-UK.org)

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*Newsletter edited by Daniel Morris. If you would like to get in touch, have any questions or feedback or you would like to advertise or make a contribution to our newsletters please email us!*