



FD Day 2020 | Medic Alert Funding | FD-UK Virtual Maccabi Fun Run 2020

Welcome...

to our Summer 2020 newsletter. You will find information on our events this year. We also feature a special on the FD Day conference and our FD-UK lifetime volunteer winner, and activities we have engaged in whilst navigating the pandemic.

Please think of us when you are giving this Rosh Hashanah. We depend on such appeals as it allows us to support our activities and FD families during the year, especially at such a difficult time, when so many fundraising activities have been cancelled.

We would like to thank you for your support and for reading this, and being part of our FD-UK community. Together we can make a difference! Wishing you all a happy and healthy year! Love from the FD-UK Committee.

Bryan King wins a Lifetime Achievement in Volunteering Award

Bryan King, is a Trustee and co founder of FD-UK (formally DSGB.) He has held key positions for over 40 years. Bryan won a Jewish Volunteering Network lifetime volunteering award for his sterling support of FD-UK.



Photo Features: Bryan King, FD-UK Trustee & Simeon Cohen, FD-UK Chairman

The FD Day Virtual Conference



The FD Day virtual conference, run by the New York Centre for Familial Dysautonomia was attended by several FD families in the UK as well as consultant neurologist Dr Hagen, who treats

FD adults. Our committee member Rosalind Jacobs writes that she was delighted at being able to attend the event for the first time, as it was live online due to the pandemic. She explains that there were over 90 families with a global line up of specialists talking about the disease and treatments. Ros says it was "unbelievable to hear the latest research in FD and to hear from the specialist in Israel and New York. " She found their accomplishments so inspiring and was impressed with their knowledge sharing, professionalism and their passion for world wide collaboration. It was reassuring and informative that they discussed FD patients who had had Covid 19, all whom had recovered. Ros felt the ability to ask questions and articulate problems so they could learn to treat aspects of FD was valued, and encourages all suffers to read their blog and complete any questionnaires and take up opportunities to be involved in their research. She explains that the more information about common ailments they have, for example, enabled them to design a treatment, to prevent eye deterioration. The online event and research opportunities are all available to view on their website and blog: www.dysautonomiacenter.com. They are also posting advice on how to reduce risk of the coronavirus infection and how to monitor health at home, and how to slowly restart life while protecting FD patients in the household.

### A little Lockdown Love for all at FD-UK

During lockdown, we sent all our FD community an Amazon voucher to enable them to treat themselves to something to break the boredom, and know that we are thinking of them and here to support them in such challenging times. We received many excited messages from recipients. Simon Woolfson wrote "I want to thank everyone for the Amazon gift voucher. It was much appreciated and thoughtful, thank you very much". Simon planned to buy and build some lego creations during lockdown with his gift.



### Medic Alert subscription and jewellery for all our FD-UK community



During this pandemic we were made aware of certain hospitals only allowing the actual patient into hospitals, at any one time. **In response to this we have contacted all our FD-UK community and have set up a charity subscription to Medic Alert. We will cover the subscription to medic alert and pay towards their chosen Medic Alert jewellery for all FD-UK sufferers.** This will enable Doctors and hospitals to access any medical notes from central system no matter where the patients are, or who may or may not be there to advocate for them. If you would like more information about Medic Alert and to take up this offer, please contact us on: [reply@fd-uk.org](mailto:reply@fd-uk.org)

### Maccabi Fun Run goes virtual during lockdown: FD-UK raised over £3,000



*In order of the photos, left to right: these little legs walked 3k; Tasha Lawrence and husband JC turned off the electronic devices; Geraldine King shaved Bryan Kings head; Simeon, Jackie and Molly Cohen walked 5k; Ros and Ian Jacobs turned off the electronic devices.*

This year due to Covid -19 The Maccabi GB Community fun run went online due to lockdown. On 24th May 2020 we raised a whopping £3,000 from our individual lockdown locations as we engaged in a range of activities from local walks, mobile phone abstinences and Bryan even shaved his head, live on youtube. This was a great challenge for all our fundraising community and committee, to think of creative ways to raise money to help those with FD at such a poignant time, when we have been hit hard with the cancellation of our

other fundraising activities. We are grateful to all those who supported us and took part and especially to Maccabi GB for helping enable us to promote our small charity and raise essential funds.

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### **Eli Freilich explored the striking landscapes of Iceland raising awareness for FD-UK**

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In March, Eli went on an adventurous trip to Iceland. He had always dreamed about doing this and he knew it would be a really challenging trip, especially with a recent knee injury. Eli camped solo in the snow in 1°C - 4°C, climbed across snowy mountains (with a tour group) and alone. At one point Eli needed to turn back because of the risk of avalanches. Eli describes the scenery as phenomenal, and he would recommend that if you can go, you should!

Eli achieved an amazing challenge (which he plans to repeat) although he is now home safe now, any sponsorship to this very important charity for this amazing feat would be really appreciated and gratefully received. If he stood in a t-shirt and slept in mountains full of snow for FD-UK, giving a few pounds from a warm home is surely easier 😊! To donate for Eli's Icelandic mountain adventure, please donate on our website: [www.familialdysautonomia.co.uk](http://www.familialdysautonomia.co.uk)



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### **The Maccabi Fun Run 2020/21, Annual Supper Quiz 2021 and Annual FD get together have all currently been postponed due to the pandemic.**

We will inform you when it will be possible to rearrange such fundraising activities (Photo: Natasha Lawrence & Ian Jacobs from Maccabi Fun Run 2019).

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### **FD-UK chosen charity for annual proceeds from Kinneret**

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The charity Kinneret has selected FD-UK to be their chosen charity for raising funds this year. Unfortunately their Spring Quiz was cancelled due to the pandemic but the proceeds of the ticket sales, collected so far, were kindly donated. Kinneret also had an afternoon tea with all funds donated to FD-UK. We are very grateful that they chose to support our charity this year.

### FD-UK Virtual Bake off

Despite Covid- 19 we are still aiming to have fun together, with a virtual bake off event, for our FD-UK community and families. I wonder who will mix up the salt with the sugar or who will get in a sizzle? If you would like to join us, please email: [reply@fd-uk.org](mailto:reply@fd-uk.org)

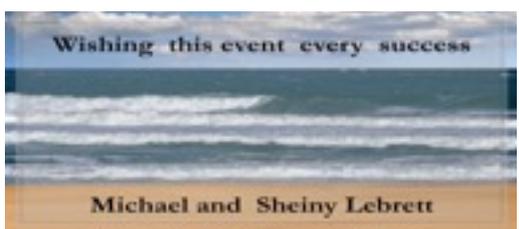


### Cook Book still available: All proceeds to FD-UK

With thanks to Mrs.Obermeister for creating our fabulous cook book as well as generating all the advertising within it. The books have been flying off the shelves in various locations and we have the last few left for special customers. It contains 172 delicious recipes. Books are £12 each. Please email us, if you would like a copy: [reply@Fd-UK.org](mailto:reply@Fd-UK.org)



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