



FD-UK Lifetime Achievement Winner | FD-UK Cookery Class | FD-UK Online Annual Quiz 2021

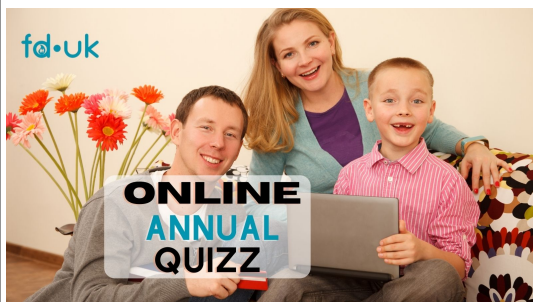
Welcome...

to our Spring 2021 newsletter. We feature upcoming events such as the FD-UK annual quiz online, our FD-UK lifetime volunteer winner, and activities that we have engaged with whilst navigating the pandemic.

Please think of us when you are giving donations this year. 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 traditional fundraising activities have ceased. Please visit our donation wall on our new website.

We would like to thank you for your support and being part of our FD-UK community. Together we can make a difference! Stay safe, Love the FD-UK Committee.

FD-UK Annual Quiz Online



Please book to join our FD- UK ONLINE Quiz. This year, for the first time, we are hosting our annual quiz, virtually. With a new quizmaster and an exciting online raffle. We invite you to join us again and please just give a voluntary donation per household. So, get the food in, tell your friends and get ready for a fun evening on the **11th April, 8:00pm – 9:30pm** or click here to book here:
<https://familialdysautonomia.co.uk/.../the-fd-uk-honesty.../>



Picture: Sarah Landau and her JVN Lifetime achievement award.

Sarah Landau wins JVN's Lifetime Achievement in Volunteering Award

Sarah Landau, is currently a Trustee and Treasurer of FD-UK and she has held key positions at FD-UK for the last 25 years. Sara recently won the Jewish Volunteering Network (JVN) lifetime volunteering award for her constant support of FD-UK

Sara has been a member of the committee since 1990. She plays a huge role at the regular monthly committee meetings and her input and management as treasurer is fundamental to our smooth running. She spends much time keeping our accounting books and records up to date, dealing with the charities commission and our end of year accounts. Sara also completes all the accounts for all our individual functions and fundraising activities and payments of invoices. Her role as Trustee involves the processing of all claims and dealing with the recipients of those claims. As a result, she is in regular communication with our FD-UK community offering support as well as feeding relevant concerns back to the committee. Sara attends all trustee meetings on a regular basis and as a trustee is involved in all decision making for the future of the charity.

We are so grateful for the time, support and skills Sara brings to FD-UK. She has such a positive impact on the committee itself, as well as the FD-UK community. All in all Sarah

is the epitome of a volunteer and a senior committee member. She is an example to us all, showing exceptional dedication and making such a huge contribution to FD-UK. With the deepest gratitude the committee and on behalf of the FD-UK community we want to thank you for all your hard work and want to tell you what a difference you have made to the smooth running of the finances of FD-UK, to our relationships with our community and to the FD-UK families who have liaised with you for such a long time.



NHS
**University College
London Hospitals**
NHS Foundation Trust
Picture: Rosalind Jacobs and her daughter Natasha Lawrence.

Rosalind Jacobs from FD-UK, becomes The Carer Governor for UCLH

Our FD-UK committee member Rosalind Jacobs, responsible for FD-UKs 'patient communications' has also been selected as carer governor for UCLH. As a parent carer Ros totally understands what it's like to live as a carer and manage all the stresses it brings to the family unit, managing appointments and learnt to deal with hospital systems and services. Ros is proud to be the voice and make a difference for carers, if the family member who you care for attends UCLH. Rosalind says "I was delighted to be voted as carer governor and to be able to represent others who live a similar life as mine and hopefully be able to shape better services for others." Rosalind also adds that "subject to a recent interview, she is also delighted and proud to be the patient voice for a further term of two years for rare diseases NHS England." We are so proud of Ros' continuation and growth in the area of patient communications where she excels in supporting families and advocating on behalf of them and FD sufferers helping to bring their voice to the forefront.



Learn to cook a crumble with your Kids!

Please book this new fun family cooking event on:

Date: 9th May 2021

Time: 2 – 3 pm

£10 per household

We are excited to introduce our new professional online cookery class, making scrumptious fruit crumble for all the family to enjoy. Everyone from age 2 and above, together with teenagers and adults can enjoy and learn to cook a crumble at new this fun online event, with a professional chef. The recipe can easily be adapted for FD dietary requirements. We will send you an ingredients list to bring to your cookery class once you have registered for the event. After the event, you will be able to replay the lesson as many times as you want for added value. Please note that children under 14 must have adult supervision.

Click to book now <https://familialdysautonomia.co.uk/.../online-cookery-may21/>

FD-UK committee had recreated a new website, gone zoom-tastic and created new online events.



Picture: Dr. Shara Cohen
FD-UK Vice Chair.

During the pandemic our Vice-Chair Dr Shara Cohen (pictured on the left) has used her digital expertise to recreate our website and make it more intuitive, also creating a new donation wall where you can donate and dedicate to a loved one or in memory of someone, if you wish. Shara has also created a new online events system to support our social media and digital presence. We are very grateful for her technical wizardry and the time she has devoted to this, we are very fortunate for her digital skills, hard work and dedication.

As a committee we now regularly host our monthly committee meetings on zoom, chaired and managed seamlessly by Simeon Cohen our Chairman. As well as creating new virtual events over the pandemic, from the up-and-coming cooking lesson and annual quiz. Last year we took-part in the virtual Maccabi fun run, in May for FD-UK and their inter-charity Quiz Night in December. We are proud to say all these technical developments have been managed voluntarily and we have not had to dip into charity funds, especially at a time when traditional fundraising has been so difficult. It is felt that integrating these new technologies and platforms into FD-UK has catapulted us into a future of online fundraising and management. As we all adapt to the next normal, our families and the committee have started to enjoy and value many aspects of this online format. Any challenges with our technologies and online platforms have been well supported and tackled head on, which is testament to our dedicated voluntary committee who (like the rest of the world) did not have the ability to plan, for this scenario. This drive may enable FD-UK, like many businesses and charities, to digitally transform and adapt into a more integrated online future. Whilst our events and committee are engaged online, we all appreciated and miss seeing each other and fundraising physically together. The virtual collaboration and commitment of our committee, to this online environment has been a great shift that has been greatly valued.

It is important to note that all our FD-UK committee is made up from volunteers. So, as well as volunteering for FD-UK our committee members are managing family members with FD who are shielding, children they are home schooling and the stresses of managing their careers and businesses during a pandemic. Several of our committee members and their family members, even caught and thank g-d all recovered well from Covid-19. Achieving what we have this year has truly been a team effort as we are all committed to giving our FD-UK community, the funds, care and support they deserve.



Picture: FD-UK Committee Meeting

FD-UK has connected with Amazon Smile



Whether 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.

Medic Alert subscription and jewelry 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 we invited all our FD-UK community to join a charity subscription to Medic Alert. 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 media alert and to take up this offer, please contact us on: reply@fd-uk.org

A little birthday cheer from all at FD-UK



Since coronavirus our FD-UK community who are medically vulnerable began shielding. Therefore, the impact of the pandemic, and isolation together with the uncertainty of when they will be able to enjoy day to day activities again, has been tough.

So, this year this as well as sending everyone a lockdown and Chanukah gift, we later decided to send all our FD community a birthday gift as well. This was a small step to show we care and remind them we are here to support them and especially giving them something they can enjoy, from us. We have received many warm, heartfelt and grateful messages when people have received them and we have been delighted to bring a little bit of cheer, at such a difficult time.

FD-UK join in a Celebration of Dr . Axelrods 80th Birthday

Picture: Dr Axelrod



On 7th February our community gathered for Dr. Axelrod's 80th birthday party on Zoom. The party was to celebrate with Dr. Axelrod and honour her lifelong devotion to caring for our loved ones with FD. Many of our FD community attended and said it was wonderful to see friends from near and far join together to celebrate Dr. Axelrod and her impact on so many lives.

After the main celebration, there was an introduction from the Head of the Foundation and a few words from the nurse who worked along side her and Professor Kaufmann, Director of NYU Dysautonomia centre. Together everyone sang happy birthday before the party split into two groups: Dr. Axelrod visited with her former patients, where she had the opportunity to speak to everyone individually, in one group. In the other was a parent group, where families shared memories of Dr. Axelrod over the years. Our committee member Rosalind Jacobs says "The patients separated and in turn told our story and shared memories happy and sad. In this couple of hours, we all laughed and cried, it was so emotional and it brought us all together from all over the world to celebrate this special women's 80th birthday. It was an honour and a total pleasure to be part of this incredible physicians' special birthday. Dr Axelrod was part of our lives for many years. She made FD her total life and with this she brought hope and support to her patients and their families. She researched and gained knowledge over her career which gave the FD patient a better quality of life and with this she was there to support you 24 hours a day 7 days a week. She maybe in a restaurant or getting on a plane but life stopped for her if her patient needed her. On the zoom party her eyes sparkled at seeing her patients who are like her own children, seeing how they had grown and strived to have a normal life with this illness. She loved taking to all of them one by one and listening while the patients told their own stories about this amazing woman. As a group could never thank enough as without her we would not have our children. Happy birthday Dr. Axelrod you are just

(Continue overleaf.)

incredible." In the FD Journal 2020 Dr. Felicia Axelrod dedicates the following inscription "In honour of all the fabulous FD patients and their incredible families. You have enriched my life immeasurably and will forever be in my heart."

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A tribute to the late Chief Rabbi, Lord Dr. Jonathan Sacks, 1948 – 2020

It is with deep sadness that we would like to take this opportunity to remember the late Chief Rabbi, Lord Dr Jonathan Sacks. He was an exceptionally talented yet approachable person, who grew up in Finchley. He attained a scholarship to Cambridge, graduating in Philosophy and continued with research to be awarded a PhD. On a trip to New York, he consulted with the late Lubavitch Rebbe who encouraged him to enter the UK Rabbinate.

He attained a double Semicha and became lecturer, then Principal, of Jews College, London. He served as Rabbi in several flagship constituents of the United Synagogue before being elected to the office of Chief Rabbi in 1991 in succession to Lord Jakobovits. He enhanced the services of the US, with the publication of a weekly sedra sheet for congregants and the production of new editions of the Siddur and Machzorim for the festivals. He was also very concerned for improving Jewish education for the next generation. He initiated the youth division 'The Tribe' and backed the move to open up more Jewish primary and secondary schools in Greater London. He was a prolific writer with many essays collected into numerous books. He was also an inspiring speaker, contributing to BBCs 'Thought for the Day'. He spoke with authority whether on issues affecting our Jewish way of life or our society in general, earning the respect of everyone both in the UK and abroad. He has made several videos regarding Holocaust Memorial, available on UTube. After retirement in 2013, he was still active in overseeing his publications and being a guest speaker at international conventions, receiving many awards and honours. Clearly, he can be credited with raising the profile of Orthodox Judaism in our society. All this was only possible with the support, encouragement and sacrifice of his dear wife Lady Elaine, who is patron of our charity FD-UK. Our deepest condolences go out to Lady Elaine, their children and all his family, wishing them all long life.

Contribution by Dr Jeffrey Freilich.

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In loving memory of Joshua David Field, 1981-2020



We would like to take this opportunity to remember what FD means to our families and community. We would like to take some time to think about the loved ones we have lost to this heartbreaking condition, especially Joshua Fields, who died in July 2020. Our sincere thoughts are with his parents Roger and Julia (nee Collis) Field. Roger and Julia grew up in Hampstead Garden Suburb and were from well known local families namely Collis, Field, Feigenbaum, Frankfurt and Minsky. Mr Stanley Frankfurt o"n, an uncle of Roger, had been a warden of the Norrice Lea (U.S) shul and against the perceived wisdom of the time, c. 1960, set up the successful Kerem Primary School . All the families were staunch supporters of the Norrice Lea community and its activities. When Joshua was born and diagnosed with FD, he was treated through the NHS and Great Ormond Street Hospital. After 2 years and with great courage, his parents headed westwards to the USA, to Dr Felicia Axelrod at NYU, where, they felt they would obtain superior treatment for Joshua. He did indeed flourish under Dr Axelrod.

On completing high school, Joshua attended Hofstra University graduating with a Bachelors' degree in History and a Masters' degree in Higher Education Leadership and Policy Study. He went on to work at the same University in Human Resources Admin., living independently in his own apartment. Sadly, he passed away peacefully in July 2020. Joshua is warmly remembered by the founding members of FD-UK (formerly known as DSGB.) We extend sincere condolences to Joshuas' entire family.

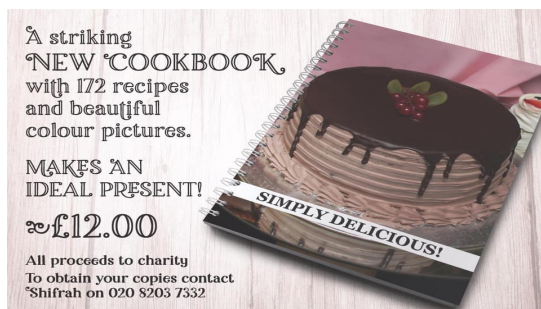
Contribution by Dr Jeffrey Freilich.



We send thoughts and love to anyone who has lost someone from FD. If you are impacted from this story please know we are there to support you and will try to help, please email: reply@Fd-UK.org

Cook Book still available: All proceeds to FD-UK

With thanks to Mrs. Obermeister our fabulous cook book, has still been flying off the virtual shelves. A few FD cook books are still available for £12. Please email reply@Fd-UK.org if you would like a copy.



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