

# NEWSLETTER

ring 20  
research & support uk



BIG  
ANNOUNCEMENT  
....coming soon

Keep an eye on your emails and social media as we have some big news coming very soon...

## All change at Ring20...

Whilst all around us uncertainties prevail, here at Ring20 we have spent much time in the last 6 months considering the needs of our member families and how best we can support you. In response to our families feeling even more isolated than normal, we commenced running online group calls entitled 'Coffee and Chat' and these have proven popular. We also created a COVID-19 information resource on our website: <https://ring20researchsupport.co.uk/knowledge-base/> with useful links to share.

But just like all charities at this time we faced challenges, losing valuable volunteers as well as fundraising income since several planned events were inevitably postponed. We do not benefit from any government or other direct funding, so we were incredibly pleased to have been successful to win two grant applications to help us through these difficult times. Some of the grant funding will help us outsource our communications for 6 months, whilst another major project is a revamp of our website, to better serve our community and attract new r(20) families.

We are sad to be saying goodbye to two of our long standing Trustees, Dr Sophia Varadkar (Medical Advisor) and Don Gordon (Chair). On behalf of Ring20 I would formally like to thank them for their valuable contributions over the years, especially Don

with whom I cofounded this group over 6 years ago, with many years prior in preparation. You will be missed.

And yet we've turned what could have been a negative into a positive...recruiting 7 new volunteers including 2 new Trustees, plus a new Chief Medical Advisor and so we are in the process of restructuring our operations to take us forward into the 'new normal'. We have an exciting fundraiser coming up, and a BIG ANNOUNCEMENT you won't want to miss coming very soon.

As always at this time of year our AGM is due and the date/time will be announced in the coming weeks.

You will have noticed that we've delivered you a pre-xmas parcel; we hope you enjoy reading this newsletter and the comics. Also enclosed is our member survey which we'd really appreciate if you could complete and return asap—if you do so online, that helps us, but if you return the paper copy in the envelope provided don't forget your stamp.

And for our UK families, we included our recycling leaflets which we'd be obliged if you could circulate safely in your local area. I'm really proud of everyone here at Ring20 and incredibly positive for the future ahead.

*Allison*

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## Patient Information Booklets

**They're here!** Our long awaited Patient Information Booklets in comic format have arrived.

Enclosed with this newsletter, every member family across the world has received 3 copies of both the younger and older years comics: 1 copy for you as a family to keep and 2 copies to give out to your medical team, school, carer or whoever you know that might benefit from understanding what living with r(20) syndrome can be like. All healthcare professionals on our mailing list have been sent a FREE copy of each booklet, too.

We hope you enjoy reading the comics and agree that they illustrate just some of the challenges that life with r(20) can bring—

although these are simply stories and not everyone's experience will be the same.

We'd love to get your feedback, so send us a photo and share your first impressions on social media.



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## Trustee News...

### Message from Don Gordon



**“I am very proud of our significant achievements thus far, which as many have recognised allowed us to ‘punch above our weight’.”**

Dear Ring 20 Friends and family - I am penning this piece with an extremely proud heart and at the same time a tinge of melancholy. After much deliberation I have to inform you that after 15 years helping to build the r(20) community, the last 6 years at Ring20 Research and Support here in the UK, I have decided to step down as your Chair and trustee to make way for a new Chair of the Ring 20 Research Support UK CIO Charity.

After deep reflection I believe that the time is right for me to create the space and time to devote to my family, for new personal and professional opportunities that are competing for my attention at this time. It has truly been a great honour to have shared in this journey with the r(20) family and the rare disease community over the past decade and have had the gift of being able to contribute to our many adventures and successes.

I am sure that the on-boarding of new trustees, volunteers and professionals over the coming months will bolster the structure and framework of the charity. This will enable us to support and put resources in place to facilitate a number of exciting opportunities and collaborative initiatives going forward.

I want to formally recognise and pay tribute to all those family members and healthcare practitioners and professionals that have entrusted their time, confidence and friendship toward me in helping to make our charity what it is today. I am very proud of our significant achievements thus far, which as many have recognised allowed us to ‘punch above our weight’. Furthermore I am delighted to tell you that given the discussions I have had with fellow trustees and having been involved in the recent appointment of new members, I sense that I am leaving the management and oversight of the charity in safe and competent hands.

Finally, I wanted to let you know that I will always maintain an interest in r(20) and the charity albeit less operationally involved. With that in view I am happy to introduce you to Neil White who will I will be handing over the position of Chair to. Neil is a very approachable well-qualified medical professional with a good pedigree of regulatory and operational experience, as well as great enthusiasm for health & community based work.

### Meet Neil White (Chair) and Lydia Hirst

I'm Neil, I'm excited to be joining Ring20. I am a Paramedic by training and have worked across the country in varied ambulance related roles specializing recently in service improvement and complex change. I hope to use my clinical experience to help grow the organisation and help it achieve its objectives. I have great admiration for families that are impacted by rare diseases and am proud to be joining an organisation doing fantastic work to offer support, research and leading the way as a patient support charity. I'm currently living in small village south of Leicester and have an 8-year-old Labrador called Sam. Sam keeps me busy and allows me to enjoy walking the canal paths around the village. I play the piano since school and enjoy musicals. I really can't cook or bake so forewarning that any treats I provide at events will be store bought!! My only claim to fame is the side and back of my head made it into a live BBC new report whilst at work, definitely an awarding winning performance!!

I'm looking forward to being able to offer Ring20 experience as a seasoned Charity Trustee as we face life in a new world as a result of the COVID Pandemic. I hope to meet everyone soon.

Hi, my name is Lydia Hirst and I'm a new Trustee for Ring20.

I am very much looking forward to learning more about Ring20: how the charity supports families as well as enabling research into this disease. In my professional life,

I worked in the chemicals industry and then set up my own management consultancy. In recent years, I have designed and delivered management and leadership training courses in the UK and abroad. Due to Covid, my training stopped abruptly last March and I am now tutoring young people in maths and physics. I intend to do this privately as well as volunteering with charities that support disadvantaged students.

Over the years, I have been involved with many charities. Most recently, I was a Trustee with Guideposts Trust a mental health and well-being charity based in Oxfordshire. I was the Chair for 5 years and prior to that a Trustee.

I hope that my skillset will be of value to the board of Ring20 and look forward to meeting many of you in the near future.



## New! Chief Medical Advisor

### Welcome Prof Sameer Zuberi

It was with great sadness that Dr Sophia Varadkar stepped down as Trustee and Medical Advisor for Ring20 earlier this year. Sophie had contributed 5 years to our patient group, helping to steer us through matters relating to healthcare and advising on all things 'medical'. In more recent times she created a Medical Advisory Board to help us navigate the unfamiliar pathways into research. It is for capacity reasons, that Sophie having taken on a more demanding role at Great Ormond Street has had to relinquish her responsibilities with us, but we thank her and wish her well.

I am delighted to advise that we are not without a Chair to lead our Medical Advisory Board.

Prof Sameer Zuberi has kindly agreed to take on the role as Chief Medical Advisor for us here at Ring20 and we are extremely lucky to have him supporting our work.

As many of you know, Prof Zuberi has spent some time researching patients with r(20) ago but his studies remain unpublished—something we hope to change.



Professor Sameer Zuberi is Consultant Paediatric Neurologist at the Royal Hospital for Children and Honorary Professor in the University of Glasgow.

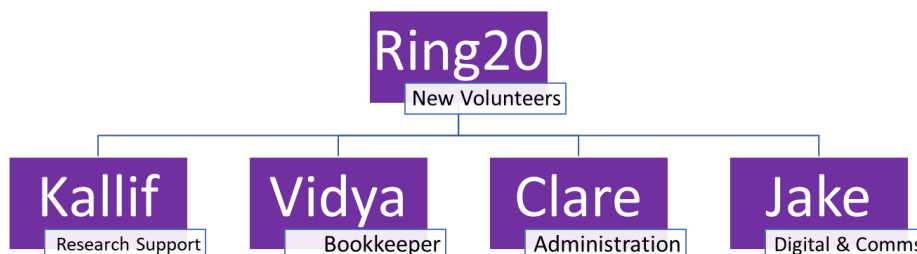
His undergraduate training was in Edinburgh, with postgraduate training in paediatrics and paediatric neurology in Edinburgh, Sydney and Glasgow.

His clinical and research interests include epilepsy, movement disorders, neurogenetics, channelopathies and neurological sleep disorders.

In 2005 he established the Glasgow Epilepsy Genetics Service and has been its clinical lead since then. He is Chair of the International League Against Epilepsy Commission on Classification & Terminology, Editor-in-Chief of the European Journal of Paediatric Neurology and Board Member of the European Paediatric Neurology Society.

### Meet our new Ring20 Chief Medical Advisor

## Say "Hi" to our newest volunteers



We also said goodbye to Dave and Audrey during the summer, as they returned to childminding duties for their families, as a consequence of the pandemic. We would like to thank them for all their support, Dave in respect of the comic workshop/production and the Big Give Campaign and Audrey in helping initiate Brighton arrangements and supporting member fundraising and welcoming newbies.

We have been extremely fortunate to have found 5 new volunteers to replace them, although we have lost another already—such are these turbulent times. Jake originally joined us as a paid intern from Keele University, (supported by Santander) but has agreed to stay on as a volunteer.

Read more: <http://bit.ly/r20Team>

Please welcome our newest recruits!





## Research

### r(20) international collaborative research

The COVID pandemic has impacted the progress of research projects and clinical trials across the world and our own planned Ring20 research study that you, our members and supporters worked so hard to raise funds for, is no exception. We are continuing to talk with Prof Zuberi and his research team to try to find a pathway forward, but we please ask you to bear with us in these difficult times.

Rest assured that your hard earned fundraising remains ring-fenced specifically for the purpose of r(20) research.

[But we don't let a problem like a global pandemic stop us here at Ring20...](#)

Oh no, we have used this summer to develop existing relationships and build new networks to form a **NEW! r(20) international collaborative research group** comprising key opinion leaders from epileptology, genomics and industry—all with a research interest in r(20) syndrome. The group comprises representatives from UK, Italy, Belgium and USA.

We've developed a Ring20 Research Strategy document that outlines our plans and direction for research into r(20) syndrome, comprising 4 main pillars:

diagnostics, prognostics, therapeutics and causes

(see below diagram).

The aims are as follows:

**Diagnostics:** improving diagnostic rates and reducing time to diagnosis.

**Prognostics:** creating/maintaining a patient registry and undertaking a natural history study

**Therapeutics:** increasing access to existing drugs or treatments

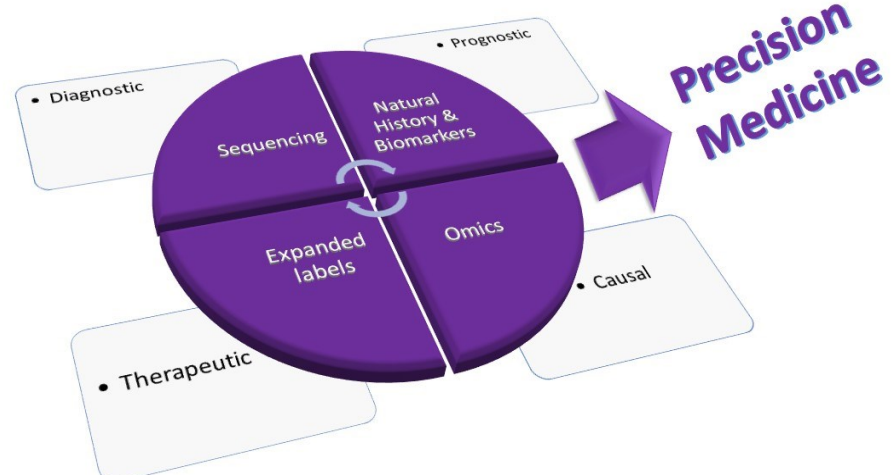
**Causes:** understanding the complex biology of the ring chromosome at a molecular level

As part of this work we are currently collaborating with the EpiCARE ERN centres to apply for funding for a future networking event to bring together the greatest and brightest minds for an innovative brainstorming conference/workshop to see what, when, why and how we can move the research forward for ring chromosomes and who can help us.

We are also in conversation with the FDA Division of Neuroscience 2 regarding how we might improve access to medicines for people with r(20) and similar epilepsies.

All of the above means Ring20 are driving the science to a new level, with a view to improving lives in the short to medium term and an ultimate goal of achieving precision medicine. None of this will happen overnight, but we have started on a journey which we hope will lead to a brighter future for those living with r(20)..

**Patients  
driving  
the research  
agenda into  
r(20)  
syndrome—  
to bring hope  
for the future**



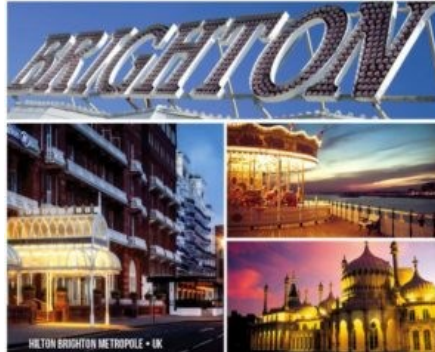


## r(20) Symposium & Families Conference

We should have been recovering now from a major event for Ring20, but unfortunately COVID-19 scuppered our plans to bring you a 2nd r(20) Families Conference and our first ever Ring20 Symposium this October—to bring you up-to-date with the latest research and to raise awareness of r(20) syndrome among healthcare professionals from across the world.

In the last 6 months and more, we have all had to get to grips with the new world of virtual meetings and that doesn't look like its likely to change any time soon—perhaps not until there is a reliable vaccine rolled out. Even then, travel may be more restricted, costs may increase due to the economic impact of the pandemic and hybrid events may become the norm of the future.

With this in mind, we have provisionally kept a placeholder for these important events in October 2021. Same venue, same month—may be an altered program. Running this event relies on more than just isolation rules and restrictions, but also funding which we have seen cut in these last months.



We will do everything we can to bring our r(20) families together again, we're just not quite sure how or when at the moment....

(provisional)  
**Families Conference 2021**  
**Fri 19th Oct – Sun 123rd Oct**  
**2021**  
**Hilton Brighton Metropole**  
**Hotel**  
**Kings Road, BN1 2FU**  
**Brighton, UK**

**r(20) Families**  
**Conference**  
**provisionally**  
**postponed to**  
**2021**

## Rare Revolution Magazine: Rare Epilepsy

Did you see the latest edition of Rare Revolution Magazine dedicated to Rare Epilepsies?

If not you could be missing out...

Ring20 submitted two articles:

- ◆ Sharing information about our new patient information comic booklets
- And
- ◆ Showing how collaboration can really help drive the rare research agenda

Allison also co-authored the EpiCARE ERN patient advocates (ePAG) article, as well as being instrumental in pulling together rare epilepsy patient support groups and healthcare professionals from across Europe and the world to contribute content for this edition, **which turned out to be the largest edition of the magazine yet—beating Rare Cancer!**

Read the full magazine online here:  
<http://bit.ly/RARE-Epilepsy>

Or go straight to the Ring20 articles:  
**With a little help from our industry friends: (page 90)**  
<https://bit.ly/34KLGCZ>  
**Educational resources: (page 94-95)**  
<https://bit.ly/3iNhjAD>

**RARE**  
**REVOLUTION**  
 MAGAZINE

Charity News



Issue 017 RARE Epilepsy Pages 90 and 94  
[www.rarerevolutionmagazine.com](http://www.rarerevolutionmagazine.com)  
[@RareRevolutionMagazine](#) #RareRevolutionM



Read Ring20's  
 RARE NEWS

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## COVID-19 response Grants

Here at Ring20 we are no different from the many other charities around the world who have been impacted by the COVID-19 pandemic.

In the last 6 months we have lost volunteers, seen a significant decline in our projected fundraising income and at the same time launched a new service 'Coffee and Chat' to meet the needs of our member families. We have also tried very hard to keep you all up-to-date with the latest COVID information through updates on our website and social media.

All of this means delivering increased vital services to you, with less people and money.

We are incredibly grateful to the Cadent Foundation and The National Lottery Fund in conjunction with the UK Government Department for Digital, Culture, Media and Sport, for supporting us with grants to help us through the next months.

These 2 grants have enabled us to upgrade our Zoom account to continue to deliver you our Coffee and Chat sessions (see over) seamlessly—we used to have to reconnect after 40 mins—as well as conduct all of our internal and external virtual meetings in a more professional and productive manner. They will also facilitate the update of our website, which is becoming unwieldy to support and not working as well as it should for you our service users.

Importantly, we will again be able to outsource our social media and eNews to RareComms to deliver on our behalf.

In these challenging times, getting the right information out, at the right time to the right people is vital and these grants will facilitate this.

**As part of our  
restructure a  
new look  
Ring20.....  
coming soon**



HM Government

In partnership with

**THE NATIONAL LOTTERY  
COMMUNITY FUND**



## New look website coming soon...

Our website is getting a makeover.

We're rebranding and you'll see a whole new look and feel to Ring20 in the coming months.

It's over 6 years since we launched our original website and we think you'll agree it needs a bit of updating. We want to make it easier for you to navigate to the information you are most interested in and we also want to encourage new visitors to our site—maybe this will include a few new families or healthcare professionals with an interest in r(20) syndrome?

It's really important that our website is accessible to all.

Do tell us if there are parts of the website you really like and/or if you think anything is missing or could be improved, as we may be able to incorporate your ideas into our new design.

We'll let you know when we go LIVE...

## Coffee and Chat

We started running our regular Coffee and Chat sessions in May 2020 to help our member families to cope and relieve feelings of isolation during the COVID pandemic and they're proving really popular across the world. Organised twice per month and alternating between the 2nd Sunday and 4th Saturday of each month, we aim to accommodate as many of our families from wherever you are located, by changing the time of day that we run the sessions.

We've had families join in from USA, Canada, South Africa, Australia, as well as the from around the UK.

Some individuals who have r(20) pop up and say "Hi" from time to time and we love to see how you are all doing.

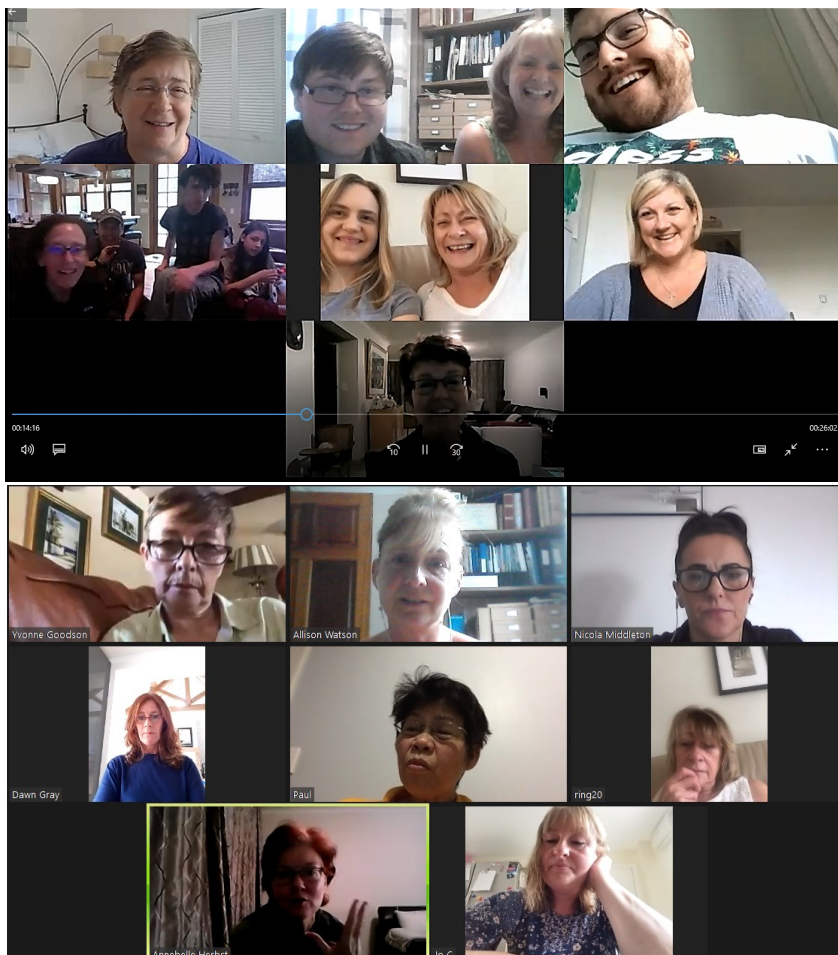
There does seem to be a majority of mum's participating, so we'd encourage some of the dad's to join us too—we don't bite, promise!

It's a great chance to catch-up with others who understand what living with r(20) every day is really like and we celebrate the highs and the lows. There's a real sense of community as we all help each other with tips and ideas to cope with daily situations.

And as you can see in these few photos, we have some fun and laughs, but also some quite serious conversations at times too.

Everyone is free to come and go as they please—there is no obligation to stay for the full 90 mins, although several of us could keep chatting for much longer :-)

As one of our mum's put it **#FoundMyTribe**



### Join Zoom Meeting

<https://us02web.zoom.us/j/94931417066?pwd=YU5qTlE4ZFUxWlR6TVVjdjU1YTlnZz09>

Meeting ID: 949 3141 7066

Passcode: ring20

You don't need any special equipment, just a PC, laptop, tablet or phone.

Just click on the link to the left and join the conversation.

**Join us on  
Zoom on the  
2nd Sunday  
17:30 (UK time)  
or  
4th Saturday  
10:30 (UK time)  
of each month**





**Support:  
At the heart of  
what we do at  
Ring20.**

## Making Connections, Supporting Families

**DID YOU KNOW?** We currently support around 120 individuals and families across the world with r(20) syndrome.

Supporting and connecting families is at the heart of what we do—it's in our name.

As you can see from our latest maps, we are quite disparately spread out—yet there are pockets of the world where we know of the most families e.g. England, or the eastern states of the USA. This is unlikely to be because the condition is more prevalent in those areas or those populations, it is most likely to be as a result of awareness to make a diagnosis, ability to find our support group and also countries where English is the native language.

Recently, families in Australia, Italy and the USA have requested to be connected to each other and we are finding ways to facilitate this. We need your permission to share your contact details first, though.

Approximately one third of all families benefitting from our services live in the USA or Canada. Connecting those families across North America makes a lot of sense, since reduced time differences mean they can communicate at more convenient times of the day.

If you'd like to be connected with other families in your own country, please contact Clare [admin@ring20researchsupport.co.uk](mailto:admin@ring20researchsupport.co.uk) who can try to arrange this for you.



**RareConnect:  
translation  
available in  
11 different  
languages**



## RareConnect

There are 25 known r(20) families in Italy according to healthcare professionals in country, however only a two or three of them participate in our support group, since language is a major barrier.

We have a solution—RareConnect—our online forum that allows exchange of information and chat in 11 different languages.

Our Ring20 RareConnect platform is not just for those for whom English is a 2nd language or not spoken at all, it allows families to connect and share experiences regardless of language, breaking down barriers.

The forum will be enriched by more families joining in the conversation.

Join our RareConnect community here:  
<https://www.rareconnect.org/en/community/ring-chromosome-20-syndrome>





## Are you on the r(20) map?



Join the map  
here:



<http://eepurl.com/c7DNST>

For access to our PRIVATE map (to connect directly with other r(20) families) you will need to supply a gmail address

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## Events

### European Congress for Rare Diseases

In May, Allison co-presented at the European Congress for Rare Diseases (ECRD) together with Tim Buckinx from epihunter (also the father of a son with r(20) syndrome).



Our talk was entitled:

Repurposing technology  
to create a new normal  
for hidden disabilities



Wherein I described the 'needs' of those living with hidden disabilities, such as people with non-motor epilepsy (which includes those affected by r(20) and Tim explained how epihunter might offer a solution.

### Epilepsy Foundation Pipeline Conference

And then in July we did it all again—at the Epilepsy Foundation Pipeline conference. On both occasions our talks were well received and seemed to hit the mark with the varied audiences.

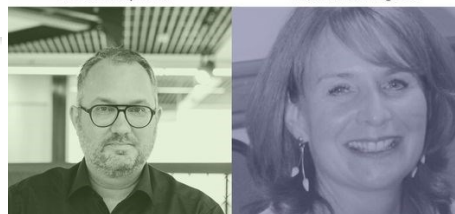


Repurposing technology to create a  
new normal for non-motor seizures

August 28th - 8.00-9.00 A.M.

Tim Buckinx, epihunter

Allison Watson, Ring 20 UK



These talks are a great way to raise awareness of r(20) and in the virtual world, you can now engage with a larger group of participants.

The recording of our presentation will be made available here shortly:

<https://www.epilepsy.com/>

Speaking at  
events helps to  
get people  
talking about  
r(20) syndrome

## Forthcoming Events

### RAREfest2020—28th Nov 20

Cambridge Rare Disease Network (CRDN) are again hosting a festival for rare diseases to engage the wider public into learning about what it is to live with a rare disease and how people all over the world are affected.

There's a great line-up of speakers, some virtual hands-on exhibits and lots of fun, cool stuff to read up on. And the best bit is its online and its FREE!

Ring20 are a media partner and will also be hosting a virtual exhibition stand for rare epilepsies featuring lots of facts and figures, video and info about r(20) syndrome.

Sign-up for your FREE virtual ticket here:  
<https://www.camraredisease.org/rarefest20/>

**It's VIBRANT  
It's VITAL &  
It's VIRTUAL!**

AN AWARD-WINNING FESTIVAL THAT IS  
AS UNIQUE AS THE PATIENTS IT CHAMPIONS

Featuring the brightest minds in rare disease research,  
the innovators of life-changing tech, the pioneers  
in rare disease medicine, and the patients whose  
powerful voices must be heard

**Join us on November 28<sup>th</sup>  
for RAREfest20**

For the experts • For the curious  
For everyone • For FREE!

For more info  
& to book FREE tickets:  
[www.camraredisease.org/rarefest20/](https://www.camraredisease.org/rarefest20/)

**CRDN**  
Cambridge  
Rare Disease  
Network

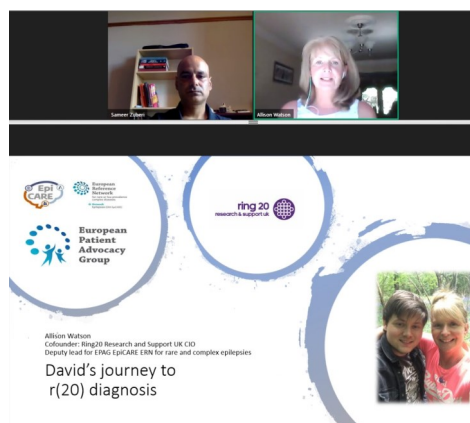
## EpiCARE ERN update



As mentioned in our previous newsletter earlier this year, there is quite a lot of activity happening in EpiCARE ERN that benefits those affected by r(20) syndrome—which is fantastic. Make sure you look out for the following:

### DID YOU SEE?

- **Webinar: Diagnosis and treatment of epilepsy relating to r(20) syndrome** – Co-presented by Prof Zuberi and Allison, You can still view the webinar here: <https://epi-care.eu/webinars/> (Scroll down the webpage to 25th June) Its FREE to register then watch!



Look out for the following which are due for publication shortly:

- Launch of **r(20) information leaflets**, one for healthcare professionals and one written for patient families. These summary leaflets are designed to provide an overview of the syndrome for newly diagnosed and/or existing patients and the healthcare professionals who manage their care. Produced by Prof Zuberi and Allison these leaflets will be available on the EpiCARE website: <https://epi-care.eu/>

- Update to **Orphanet** which is way overdue having not been looked at since 2006. Allison has worked on this with Dr Valentina de Giorgis (Italy). Search for Orpha 1444 on [orpha.net](http://orpha.net)

Another initiative in the pipeline...

- An **e-Learning module** for specialist training for epileptologists is being developed over the next year for several rare and complex epilepsies, including r(20).

## r(20) Patient Journey

In addition to all of the above, our EpiCARE Patient Advocacy Group (ePAG) have been working together developing **patient journey's** for each of the rare epilepsies we represent and of course, we have drafted one for r(20).

The ultimate objective is to publish our r(20) patient journey, so:

- Families expectations can be managed both now and into the future and they are alerted to what challenges they might face; and
- Healthcare professionals can truly understand the reality of what people with r(20), experience in healthcare not what is 'supposed' to happen.

Of course as many of our member families know there is no such thing as a 'typical' **r(20) patient journey**, because we all follow slightly different paths to diagnosis, testing, treatment, care, support and so on.

What is important though is capturing the steps along the path that we all have to follow and recognising good practice where it exists and should be replicated and where the patient experience can be improved. **We call this identifying our 'unmet needs'.**

We've recently asked our family members to validate draft r(20) patient journey on our Coffee and Chat calls and through our CLOSED Facebook group for requests for feedback, as the draft was originally designed based on Allison's experience with David, but needs to now be expanded to be more generic.

Whilst we have made some updates thanks to the comments received, we'd still like more of you to input. We included the latest draft over for you to review. Please pass any comments back to [allison@ring20researchsupport.co.uk](mailto:allison@ring20researchsupport.co.uk)

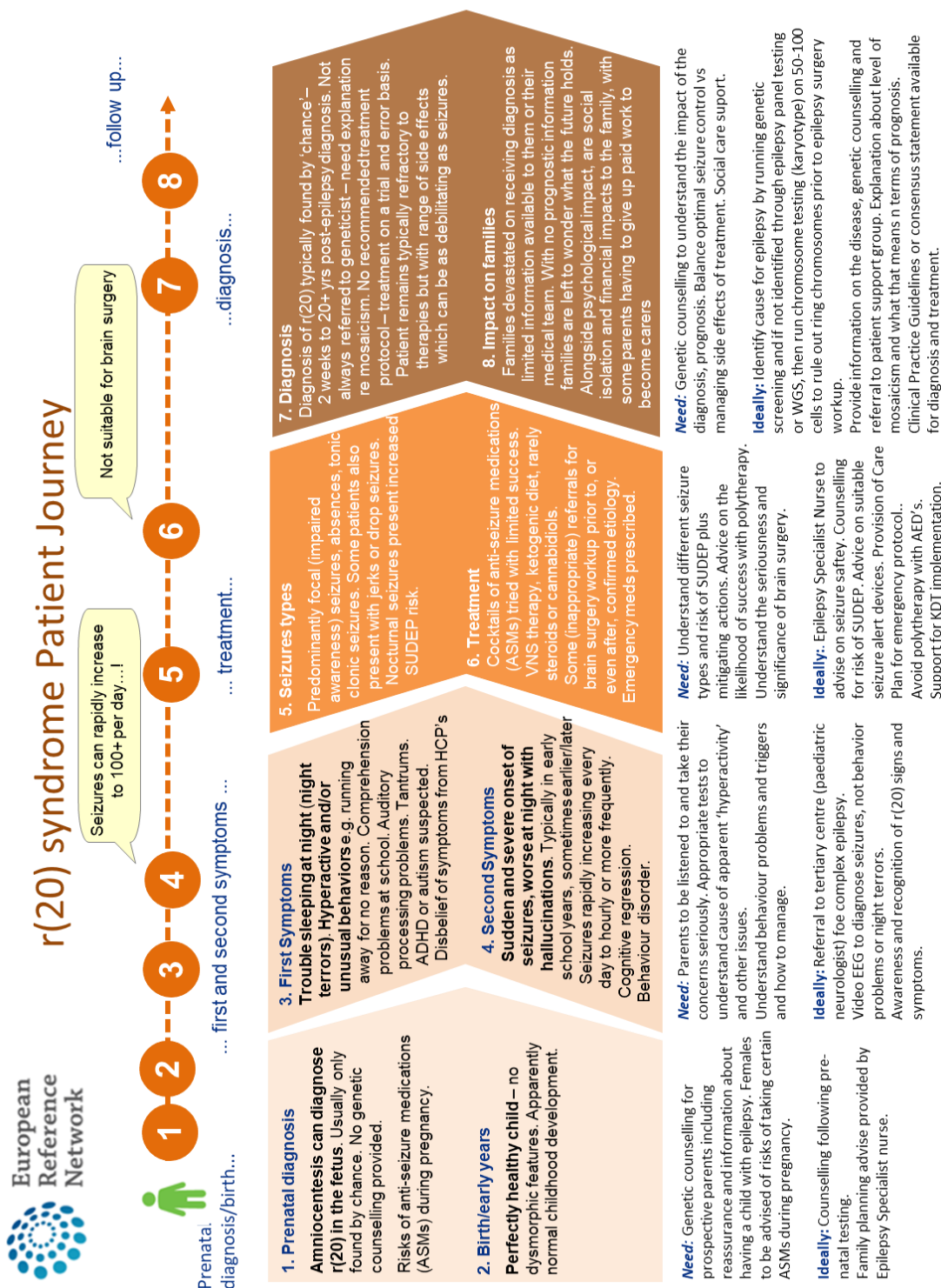
The final journey will be presented in a meeting in Rome in December 2020.

**Raising the profile of r(20) and other rare and complex epilepsies across Europe**





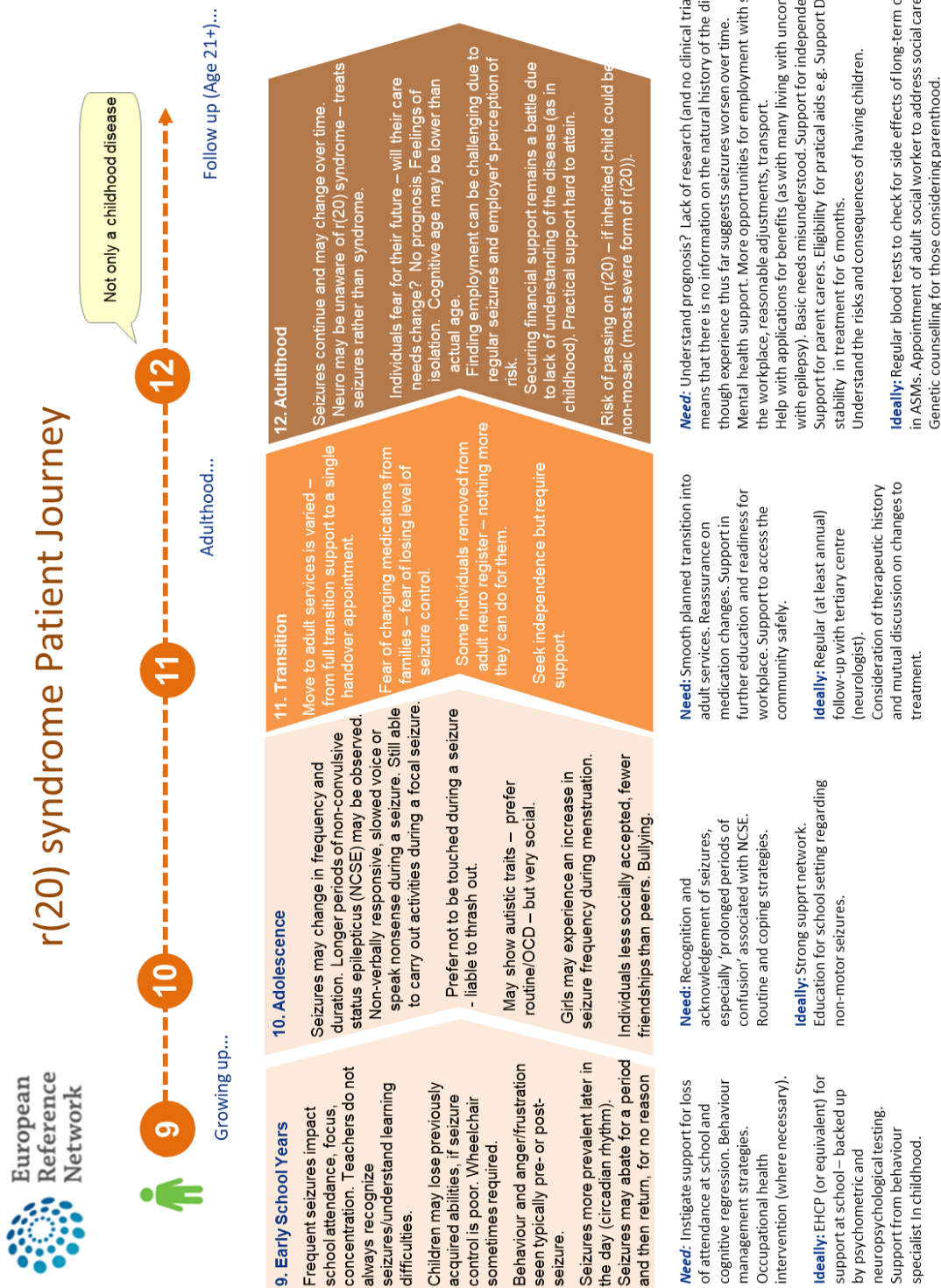
# r(20) syndrome patient journey



With special thanks to the r(20) families who helped to create this journey and contributed their personal experiences for the benefit of others.



# r(20) syndrome patient journey (part 2)

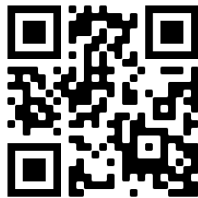


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## Fabulous Fundraisers!

**Make a  
one-off  
donation or  
set-up a  
regular  
donation  
via PayPal  
here:**



<http://bit.ly/r20PayPal>

As you all know, our research and support services would not be possible without the amazing fundraising efforts of all our members, their families, friends and work colleagues!

*Several of our member's planned fundraising events have been postponed indefinitely due to COVID-19:*

**3 Peaks Challenge—Carl Darby**  
**Tombola—Nicola Middleton**  
**Pub Fundraiser—Dale Ward**  
**Ring20 Skydive**

However, we have been very lucky to have secured some wonderful donations from individuals and corporates in the last 6 months, which ensures that we can continue to operate. We'd specifically like to thank:

- ◆ Martin Fenner for a generous donation
- ◆ Jessica Haggerty for hosting a Body Shop raffle
- ◆ Veronique Ford for putting out one of our collection pots

And Corporate donations from:



Shared  
Services  
Connected  
Limited

**WESTERN POWER DISTRIBUTION**

*Serving the Midlands, South West and Wales*

HUGE thanks to everyone concerned!

## Regular Donations

Every donation helps us to help you or another r(20) family in need.

We don't charge a membership fee for our services and don't intend to do so, as we want Ring20 to be accessible to all.

Could you spare a small amount each month or support us on an ongoing basis?

Your support could ensure that Ring20 are there for you today and tomorrow.

Consider making a regular donation either by standing Order (UK only) by completing the form opposite and handing to your bank (please send a copy to us for our records) or via PayPal: <http://bit.ly/r20PayPal>

DETAILS  
COMING  
SOON...

## NEW! Ring20 Festive Fundraising

We will shortly be bringing all our r(20) families and their friends the chance to get involved in a fun, Festive Fundraiser.

Over a period of 2 weeks, commencing 21st November 2020 we invite you to join us for our first ever virtual family quiz, as well as encouraging as many of you as possible, to run a pre-Christmas raffle in your local community (sticking to COVID guidelines of course).

We hope that you will join us and get involved.

More details coming out to you via email and social media over the coming weeks.

We have a new fundraising committee led by Clare and Dawn Gray, with Kallif supporting. Contact Clare for more information: [clare@ring20researchsupport.co.uk](mailto:clare@ring20researchsupport.co.uk)

# STANDING ORDER FORM



**Registered Charity Number 1165651**

The easiest way to support Ring20 Research and Support UK CIO is by donating regularly with a standing order. As well as being more convenient for you standing order donations help us plan ahead with more confidence.

FULL NAME:								
ADDRESS:								
POSTCODE:								
EMAIL:								
BANK NAME:								
BANK ADDRESS:								
BANK POSTCODE:								
SORT CODE:								
ACCOUNT NAME:								
ACCOUNT NO:								
Please pay the sum of : £			Every month		quarter		year	
Commencing on:	/ /		(please insert a start date)					

Until this order is cancelled in writing by the account holder. This standing order is payable to HSBC Bank plc, Brentwood Essex CM14 4RU Sort code: 40-13-22 Account Number: 81871668 for the credit of Ring20 Research and support UK CIO



Download to copy of his form from our website.

# Everyone can help with fundraising...even during COVID-19!

You don't have to host an event or even leave home to raise funds for us...

**Do you shop online?** Then are you signed up to either of the following where you can raise donations for Ring20 every time you shop online at no cost to you:



**Are you more of an outdoors person?** Then have you got: **fit4Change** - this app on your mobile phone raises 5p for every mile you walk, run or cycle. You don't have to be super fit—just use when walking the dog, going to the shops or school run.



QR code IOS

QR code Android



## Have unwanted items?

Sell them on eBay and donate 10-100% to Ring20.

<https://www.charity.ebay.co.uk/charity/Ring20-Research-and-Support-UK-CIO/71688>

Or play the **Essex Lottery**—£1 for a chance to win a £25,000 prize every week! Ring20 receive 50% of ticket sales when you support our charity:

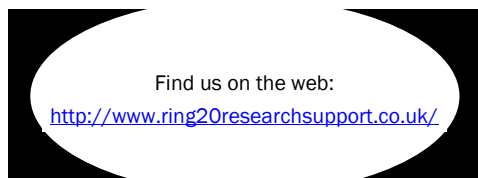
<https://www.essexlottery.co.uk/support/ring20-research-and-support-uk-cio>



## Ring20 Research and Support UK CIO

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Warley  
Brentwood  
Essex  
CM14 5BN

Phone: 00 (44) 7385 292797  
E-mail: [ring20@ring20researchsupport.co.uk](mailto:ring20@ring20researchsupport.co.uk)



*Supporting families, individuals  
and professionals affected by  
or who come into contact with  
Ring Chromosome 20 Syndrome*

## Recycling for Good Causes

### How about recycling?

Could you give out any leaflets for us e.g. at your local school, workplace, friends/neighbours, or even in clinics or GP surgeries? We can earn money from old watches, unwanted gold, silver or costume jewellery including damaged items and foreign or UK bank notes Request leaflets from [ring20@ring20researchsupport.co.uk](mailto:ring20@ring20researchsupport.co.uk)

These guys also accept used stamps.

We hope you have enjoyed reading our latest newsletter.

If you wish to receive future editions (we produce these periodically, approx. 6 monthly), please ensure you sign up to our mailing list on our website here:

<http://www.ring20researchsupport.co.uk/>

Any feedback on content and what you'd like included in future editions, please contact us to let us know. And of course, we would welcome any contributions of your own for inclusion.



**ring 20**  
research & support uk

