

## MEMBERS' WEEKEND 2019 PROGRAMME – SATURDAY 18 May

Registration will open at 10am with refreshments followed by an exciting programme of activities for all ages.  
Plan your day now!

	Tower Suite (Main Room)	Victoria Room	Hamilton Room (Children's Activity Room)	
10.30 – 10.55am	<b>Welcome to DEBRA Superhero's Weekend</b> DEBRA CEO Ben Merrett	<b>Chill Out Cave</b> Young Adults Assemble! (12 – 30 years)	<b>Superhero Boot Camp</b>	
10.55 – 11.40am	<b>Research Today -Morning Session</b> <b>Gene Editing for All Types Of EB</b>  Update on Research into Potential EB Therapies at the University of Dundee – Peter van den Akker and Aileen Sandilands  Gene-Edited Skin Grafts For JEB and RDEB – Michele de Luca		<b>Arts &amp; Crafts</b>  Choose which superhero you are or create a new secret Identity with the magic photo mirror	<b>"Marvel In Creating Super Smashing Balloon Models"</b> with Magic Dave 1 x workshop <b>11.00am-12.00pm</b>
11.40 – 12pm	<b>Over The Wall &amp; DEBRA Family Camp</b> Allan Jolly			
12 – 1.45pm	<b>Lunch in the Park View Suite, Parklands Restaurant, Garden Room, main hotel</b> <b>Deserts, Tea and Coffee</b> back at the bandstand/Tower Lounge <b>Meet with the team, look at Exhibition stands, and play the giant games</b>			
1.45 – 2.30pm	<b>Annual General Meeting followed by a Q&amp;A Session</b> Led by DEBRA Trustees	<b>"Ensure you get the dressings you need".</b> Workshop by Nurse team & Molnlycke Healthcare	<b>Superhero Boot Camp</b>	<b>A Magician workshop</b> <b>"Learn Super Powers"</b> With Super Human Russ Brown 2 x workshops 1.30 – 2.15pm & 2.30 – 3.15pm
2.30 – 2.45pm	<b>Welcome from our New President</b> – Simon Weston CBE			
2.45 – 3.10pm	<b>Are Benefits &amp; Universal Credit Your Nemesis?</b> De-bunking Myths & What Help We Offer? DEBRA's Own Justice League (EB Community Support Team)	<b>Balance Your Universe</b> Find The Superhero Inside You! Workshop with Lynne Hubbard Specialist EB Dietitian		
3.10 – 3.50pm	<b>Research Today -Afternoon Session</b> <b>Biotechs Update</b>  QR-313 – Developing RNA gene therapies for EB – Tita Ritsema  Amryt Pharmaceuticals, Oleogel S10 Clinical Trials in EB Research – Miriam Barry	<b>Tackle the Highs &amp; Lows of Life with EB</b> Become A Caped Crusader In your Family. Workshop with DEBRA's Community Support Team	<b>Arts &amp; Crafts</b>  Choose which superhero you are with our accessories or create a new secret Identity with the Magic Photo Mirror	<b>"Marvel and take part in creating super smashing balloon models"</b> With Magic Dave 1 x workshop 3.15-4.15pm
3.50 – 4.10pm	<b>Helping to Understand &amp; Manage the EB Foot "Taking one step forward"</b> - Tariq Khan, Consultant Podiatrist, EB Department, Great Ormond Street Hospital	<b>Chill Out Cave</b> For Dads and men over 18 (to be continued at secret location at 5pm)		
4.10 – 4.40pm	<b>Research Today -Afternoon Session</b> DEBRA Research Update – Eleanor Krall	<b>Chill Out Cave</b> For Mums and Ladies over 18		<b>A Magic Workshop</b> <b>"Learn Super Powers!"</b> With Super Human Russ Brown 1 x workshop 4.15 – 4.55pm
4.40 – 4.55pm	<b>GLOVE Project Update</b> Rachel Box & Healthcare Team			

The day will end with LEMONADE AND CUPCAKES FOR EVERYONE, THE CHILDRENS afternoon tea PARTY and superhero award ceremony at 5pm ON THE TERRACE AT THE MAIN HOTEL

## MEMBERS' WEEKEND 2019 – PROGRAMME

### SATURDAY EVENING

- 7pm** Drinks reception/canapes & Magician in Hamilton Rooms (bandstand if weather permitted)
- 7.30pm** Dinner (magic show commencing at 8.30pm)
- 9.30pm** Superhero disco
- 11.30pm** Bedtime!

### SUNDAY MORNING

- 7.30 – 10am** Breakfast in the hotel's Parklands Restaurant
- 8.30 – 10.30am** Breakfast club – Drop in and chat with some of Community Support team and other Members (Breakfast area)
- 9.30am** Theme park and zoo gates open, don't forget to collect your tickets from the hotel reception Desk
- 10am** Latest bedroom check out
- 10.30am** Say goodbye to the DEBRA team and enjoy your day in the park. Theme park rides open.
- Please note, lunch and various refreshments are available in the park at your own cost.*
- 5.00pm** Drayton Manor Theme Park and Zoo closes

*\*\*This programme is subject to small changes. A full programme will be handed out on the day of the event.*

### Additional opportunities throughout the weekend

Don't forget to meet the EB Community Support Team. Private appointments are available with the EB Community Support Team (a.k.a. DEBRA's Own Justice League). Visit the stand in the Tower Lounge to book.

### Not all Superheroes wear capes!

Nominate your own superhero within your family, neighbourhood, in DEBRA and the EB clinical teams. This is a great opportunity to honour the person and to share with others how people close to you make a difference. Take and return a nomination form from the Superhero stand.

### Feedback

Complete the feedback form on the day and pop it in the box or give to DEBRA staff. We really do rely on you to help us to plan for future events so please do share your feedback and ideas, especially if you would like to suggest a future location or venues, or activities and talks you would like to see.

**Our DEBRA Trustees, Debra teams, healthcare professionals and researchers will be there for you to meet throughout the day.**

**There will be opportunities for you to win prizes throughout the day – lookout for the special superhero prizes!**

**All children and adults are welcome to come dressed up in superhero outfits, t-shirts or own creations (optional).**

**Great opportunity for you to catch up with old friends and make new ones.**

## Presentation Information – Tower Suite

### **Are Benefits & Universal Credit Your Nemesis?**

DEBRA's Own Justice League (EB Community Support Team) De-bunk Myths & show what help we can offer you. Including answering questions such as, should I apply for DLA or PIP? Am I eligible for Carer's Allowance? What happens when my claim is denied and an overview of benefits, Universal Credit, DLA and PIP with real case studies.

### **Helping to Understand & Manage the EB Foot "Taking one step forward"**

EB Podiatrist Tariq Khan helps to understand and manage the EB Foot

Get practical advice that you can use to help with podiatry related problems and learn about what a difference the EB podiatry guidelines can make. Find out how we are developing a network of podiatrists who can help people with EB throughout the country, research taking place right now and plans for future studies.

### **Over the Wall and DEBRA Family Camp – Coming Soon!**

Over The Wall encourages campers to become the hero of their own stories. Their therapeutic recreation programme focuses on helping campers who experience health challenges to realise their incredible abilities and talents. DEBRA are partnering with Over The Wall to create a unique bespoke and seriously fun camp in 2020. Come and hear about our plans.

## **EB Focused Workshops – Victoria room**

### **Young Adults Assemble (Bat Cave/Victoria Room) Ages 12 – 30**

A VIP lounge strictly for ages 12+ with an opportunity to meet, socialise and chill out with other young people in a relaxed session. Design a personalised festival style wristband, find out about and some fun and useful apps, play some board games and discuss some exciting plans for this age group including a possible online chat group for invited Members aged 12 – 30 living with EB.

### **Balance Your Universe**

Workshop with Lynne Hubbard, Specialist EB Dietitian.

From Iron Man to Vita-Girl, find the superhero inside you!

Sharing advice and tips to balance your nutrition and improve your health.

### **Tackle the Highs & Lows of Life with EB – Become A Caped Crusader In your Family**

An informal, round table discussion, with some topics for discussion: bullying, family support, cultural issues, education, transition between adult and children's services, work and independence.

### **Chill Out Cave for Dads and men over 18 – Batman V Superman**

Even superheroes need some down time and support. This relaxed session aims to give Dads and men over 18 space to network with others in similar circumstances. Explore some of the common challenges and find out if you identify more with Batman or Superman. With non-alcoholic beer and wine tasting!

### **Chill Out Cave for Mums and Ladies over 18 – Wonder Woman V Elastigirl**

We all know superheroes need some down time and support. This relaxed session aims to give Mums and ladies over 18 space to network with others in similar circumstances. Explore some of the common challenges and find out if you identify more with Wonder Women or Elastigirl. With non-alcoholic beer and wine tasting and a surprise treat!

### **Ensure you get the dressings you need**

This workshop, led by the nurse team & Molnlycke Healthcare, will offer an insight in to dressing regulations, research and manufacturing. Have your opportunity to provide formal feedback on the dressing range, the good and the bad, to help ensure you get the dressings you need. Regulations for CE marks are changing and it's vitally important the EB community have their say. (This workshop is open to everyone whether or not you already use the Molnlycke dressing range).

## Researcher Speaker Information

### **Dr Peter van den Akker: Update on Research into Potential EB Therapies at the University of Dundee**

Dr Peter van den Akker is the DEBRA funded Clinical Research Fellow currently working on a project to “silence” the genes that cause some types of EB. Dr van den Akker is clinical geneticist whose training began in the multidisciplinary EB clinic of the Dutch Centre for Blistering Disorders in the UMC Groningen (the Dutch National EB Centre) in 2006. In 2008, he joined the McLean Lab in Dundee University to research filaggrin, a skin protein involved in EB and eczema. DEBRA funded the clinical fellowship in October 2015 to develop protein modification therapy methods at the McLean lab. The research now primarily focuses on a method called exon skipping. To continue this promising work, DEBRA have extended the funding.

### **Dr Aileen Sandilands: Update on Research into Potential EB Therapies at the University of Dundee**

Dr Aileen Sandilands is a molecular biologist and Senior Research Fellow at the University of Dundee, and has been working on dermatology-related genetic disorders since joining the group of Professor Irwin McLean in 2001. As part of this group Aileen helped to identify the filaggrin gene as a major genetic risk factor for eczema, a key discovery at this time. Aileen has worked with Dr Peter van den Akker before, when he joined the lab in 2008, and is now working with him again on his DEBRA funded project to modify faulty proteins in some types of EB.

### **Michele De Luca, MD: Gene-Edited Skin Grafts For JEB and RDEB**

Michele De Luca, MD is Director of the Centre for Regenerative Medicine “Stefano Ferrari”, University of Modena and Reggio Emilia, and Scientific Director and Founder of Holostem Terapie Avanzate S.r.l. Michele De Luca is internationally recognised as a leading scientist in epithelial stem cell biology aimed in regenerative medicine and has played a pivotal role in stem cell therapy and gene therapy. He is currently coordinating several early-stage clinical trials using stem cells to develop cell and gene therapies for genetic skin conditions including EB. During these studies, Michele De Luca and Graziella Pellegrini broke new ground, with a pioneering skin grafting procedure, which used genetically modified stem cells to reconstruct a fully functional outer skin – or epidermis – for a child with Junctional EB.

### **Tita Ritsema: QR-313 – Developing RNA gene therapies for EB**

Tita Ritsema, PhD, is a Vice President at ProQR Therapeutics NV, and has been involved in research at universities for almost 20 years. For the last 12 years she has been working on developing medicines which are in different stages of preclinical development for orphan diseases, mainly focusing on gene therapy. Since May 2012 she has worked for ProQR, which is a company fully focused on RNA-repair therapies for rare and ultra-rare conditions. She is currently Head of Dermatology with Dystrophic EB as her focus.