





DEBRA MEMBERS' WEEKEND


★ ★ ★ PROGRAMME ★ ★ ★


De Vere Wokefield Estate,
Reading, RG7 3AE

14TH-15TH MAY 2022

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 @CharityDEBRA

 @CharityDEBRA

 DEBRA-uk


debra

for people whose
skin doesn't work
we do

WELCOME

We would like to thank you all for coming to this year's DEBRA's 2022 Members' Weekend.

After several years without being able to get together at Member events like this, it is a special event for us this year. We are so pleased to be able to return to having the opportunity to meet and connect as a community, sharing knowledge and experiences, supporting each other, and building friendships.

Finding connections is particularly relevant this weekend as it is the close of Mental Health Awareness Week which this year focussed on the impact of loneliness and the benefits that connecting to others and the world around us bring as a way of protecting our mental health and reducing feelings of loneliness.

In putting today's programme together, our aim is to offer a mix of formats from presentations and panel discussions to workshops or informal drop ins. There are informative sessions on topics from research to footwear, diet to dressings with experts in the fields of research and healthcare. There are sessions on happiness and emotional wellbeing, workshops, activities and meet ups for teenagers, outdoor games, circus skills, dancing and creative drop-in sessions. We hope that there is something for everyone and that you will find the day not only useful but fun too.

Our Membership Team and Community Support Team will be around all day to help facilitate your enjoyment of the day and will be pleased to help where they can.

Most importantly, we hope you enjoy this year's Members' Weekend and have a wonderful time meeting old friends and new.

Best wishes



Claire Mather

Director of Healthcare,
Membership & Community Support



Helen Weaver

Membership Deputy Director



Karen Thackray

Membership Manager



HEALTH AND SAFETY



Child safety

Parent/guardian(s) are responsible for their children at all times and must not leave them unattended. The only exception is specific young person sessions (see programme). Children and young people between the age of 11 and 18 will only be able to attend the young person sessions/lunch on their own if parents have given written consent for them to do so. Parents should go to the registration desk to complete the necessary form.

Wokefield Estate is a public place, please be aware of all hazards including golf balls and two lakes on site. The outdoor courtyard area and circus skills zone is not enclosed.

Please do not allow children near the hot drinks stations, as these will not be attended.

In the event that a child goes missing or a lost child is found, please report this immediately to the DEBRA registration desk.



Identification

Event wrist bands must be worn at all times during the day and evening event to enable you to access to the DEBRA activities, meals and drinks. Wristbands are also to identify you from the public. Please remember to keep it on, even if you have a shower in the evening. Name badges should be worn throughout the day and handed in as you finally leave the venue.



Medical

First Aid - If you need assistance speak to a member of the hotel staff or DEBRA team.

Dressing changes - If you need to rest or change dressings, please go to the hotel reception desk and request access to our 'DEBRA' medical/changing room.



Allergies or special dietary requirements

Please ensure you inform staff and check that the food you are being served is suitable for you/your child's needs. There will be times when food and hot drinks are left unattended.



Fire alarm

A siren means **EVACUATE** using the nearest fire exit and make your way to the Fire Assembly Point.

Please familiarise yourself with your surroundings and be aware of the fire exits.



Activities/entertainment

Due to the wide range of attendees, we cannot guarantee that every activity will be suitable for everyone. Please consider if an activity is suitable for you or your child/young person or speak to a member of the DEBRA event team if you wish to discuss anything.



Preparing for all weathers

Remember to bring what you may need for the day, for example preparing for both chilly or sunny weather.



Have a question or need assistance?

Look for a member of the DEBRA event team, wearing green DEBRA staff T shirts, or go to the DEBRA registration desk.

We hope you enjoy the weekend.

RESEARCH, WELLBEING AND HEALTHCARE



DEBRA new research strategy

Hear from Director of Research, Dr Sagair Hussain about our new five-year research strategy which brings a step change in our approach to funding and how we will put the patient first and work with researchers, organisations and government to achieve tangible outcomes faster.



New innovations to reduce scarring in EB patients

Professor Liam Grover talks about two research projects at the University of Birmingham: the development of a new spray to treat and prevent the scarring that affects the membranes in the body which characterises EB and an oral spray for EB patients who experience blistering in the mouth.



Walking in EB patients & the Gait project

Valter Devecchi outlines the research project at the University of Birmingham looking at the challenges of walking for patients with EBS and the pilot study in a gait laboratory measuring these effects to enable the development of custom-built shoes and insoles.



Shoes, socks & the challenge of footwear

A workshop exploring the challenges of fragile skin and foot blisters when finding shoes and socks with the goal of achieving comfortable feet for all EB types. Helen Weaver and the Membership Team lead a discussion session covering footwear, socks, insoles and what works for you.



Unlock Your Well-Being

Anne-Marie Gawen is a Wellbeing and Mental Health Trainer who has worked in the NHS and Social Services. Learn about the Science of Happiness and strategies for Emotional First Aid. Accessible, enjoyable, interactive.



Ask the experts

An opportunity to ask specific healthcare questions or general queries about everyday life with EB, gain knowledge and share experiences. Questions are encouraged during the session or in advance at the registration desk. Includes panel members with lived experience of EB, Community Support Team and EB clinicians.

INFORMATION, SUPPORT AND FUN

These pages give a brief overview of some of the day's sessions. Please also check the programme timetable and our event information board.



EB skin, hair and teenage years

A workshop for parents and young people/teens alike with Sophie Randall, EB Clinical Nurse Specialist at Great Ormond Street Hospital. Useful hints and tips for growing up with EB into adulthood including topics such as personal hygiene, deodorants, haircare, hair removal, underwear, make-up and more.

Time to talk

A workshop for all parents to share and discuss their experiences. Facilitated by Dr Sarah Mundy, a Consultant Clinical Psychologist with EB and parent of children with EB.

Transition to Adult Services

Find out how the Solihull team of EB Clinical Nurse Specialists transition patients to adult services. It's good to start preparing early - so learn more and bring your questions for the nurses.

Community Support

Take the opportunity to come and talk to the Community Support Team. Bring your coffee and join us in the community cafe area or find us in our sessions. The Community Support Team offer information and support with any challenges you may have including increasing household costs, going to school and getting around plus so much more.

Dressing difficult areas

Workshop led by Gemma Harrison, EB Clinical Nurse Specialist, with demonstrations and tips on dressing difficult areas. Whether you find the neck, knee or armpit challenging, join this workshop and share your experience and tips with the group.

From pom poms to circus skills

Get creative with cartooning, card-making, design a gratitude journal and pom poms. Join Oojamaflip to try your hand at juggling, diablo and plate-spinning or get active with giant outdoor games.

Can you do the DEBRA stroll

Member Vie Portland will teach a fun, simple dance that you can do alone, or with a group of people, and that can be danced to all types of music. Don't be shy - show us your moves! No dance experience necessary and suitable for all ages and levels of mobility.

The wonders of vitamin C

Lynne Hubbard, EB dietitian, talks about the benefits of vitamin C and EB.

The DEBRA journey: Changing lives faster together

A relaxed, informative interview from parent trustee Carly Fields.

*Disclaimer: Please note activities, rooms and presenters may be subject to change

★★★ MEMBERS' WEEKEND SATURDAY MORNING TIMETABLE ★★★

Time	Wokefield 1 Suite Main Room	The Parry Room Workshops	Wokefield 2 Suite Live Stream / Chill Out Room	The Courtyard Room	Outside Courtyard	The Avenue
10.00 - 10.30am	Coffee & registration in The Avenue		All day activities Book corner Baby & toddler zone Board games		All day activities Giant outdoor garden games available Try Jenga, Connect 4, chess and draughts	All day activities Coffee & registration Exhibition stands Check out information and resources Community Café Area Bring your coffee and have a chat Stop here to be introduced to other members 10.50 - 11.20am Juggling the Education System Community Support Team stand session drop-in Meet DEBRA staff and trustees Room map provided on page 10
10.30 - 10.40am	A warm welcome Tony Byrne DEBRA CEO					
10.40 - 10.50am	Meet the DEBRA Research Team Dr Sagair Hussain					
10.50 - 11.20am	New innovations to reduce scarring in EB patients Professor Liam Grover	Transition to Adult Services Solihull EB Nurses - Drop in	Pom Pom Away Drop in Creative session		Circus skills with Oojamaflip workshop for 11 -18 year olds*	
11.20am	Break	Break		Break	Break	
11.30 - 12.10pm	Walking in EBS patients & the Gait project Valter Devecchi	Dressing difficult areas Gemma Harrison EB Specialist Nurse		An App for EB & DEBRA Share your ideas Sophie Jones, Engagement	Outdoor games available	
12.10 - 12.25pm	DEBRA new research strategy Dr Sagair Hussain		Comic Strip Creations Drop in Creative session		12.10 - 12.50pm Circus skills with Oojamaflip workshop for all ages	
12.30 - 1.00pm	The science of happiness - Unlock Your Well-Being Anne-Marie Gawen	Shoes, socks & the challenge of footwear Helen Weaver & Membership				
1.00 - 2.25pm	Lunch in The Pantry *Young members’ lunch table 11-18 year olds meet in the Courtyard room			*Parents please complete permission form at registration desk. **Please note activities, rooms and presenters may be subject to change.		

★★★ MEMBERS' WEEKEND SATURDAY AFTERNOON TIMETABLE ★★★

Time	Wokefield 1 Suite Main Room	The Parry Room Workshops	Wokefield 2 Suite Live Stream / Chill Out Room	The Courtyard Room	Outside Courtyard	The Avenue
2.30 - 2.40pm	Keep in the DEBRA loop Latest launches & resources	Emotional first aid Unlock Your Well-Being Anne-Marie Gawen	2.15 - 3.00pm Card craft Drop in Creative session	2.30 - 3.00pm Dance session with member Vie Portland Learn the ‘DEBRA Stroll’	Outdoor games available	All day activities Exhibition stands Check out information and resources Community Café Area Bring your coffee and have a chat Stop here to be introduced to other members Meet DEBRA staff and trustees Room map provided on page 10
2.40 - 3.00pm	The wonders of vitamin C Lynne Hubbard Dietitian					
3.05 - 3.35pm	The DEBRA journey: Changing lives faster together Parent trustee Carly Fields	EB skin, hair and teenage years Sophie Randall EB Clinical Nurse			Circus skills challenge Test your juggling, hoopla & balance	
3.35pm	Break	Break	3.30 - 4.15pm Decorate a gratitude journal Drop in Creative session		Break	
3.45 - 4.00pm	Balancing life - Need a safety net? Community Support Team				Outdoor games available	
4.05 - 4.40pm	Ask the experts Healthcare & EB Community Panel	4.30 - 5.00pm Time to talk for EB parents & guardians Dr Sarah Mundy				
4.45 - 5.00pm	Special message from Tom Holland Thank you and close					
5.00pm	Hot Dogs on the lawn in the Courtyard for all					

*Parents please complete permission form at registration desk.
 **Please note activities, rooms and presenters may be subject to change.



SATURDAY EVENING EVENTS



5.00pm	For guests staying overnight, please collect your keys from Reception
7.00pm – 7.30pm	Pre-dinner drinks reception in The Avenue*
7.30pm – 7.45pm	Take seats for dinner in the Wokefield Suite
7.45pm – 9.30pm	Dinner and live entertainment
9.30pm – 11.00pm	Disco and performance of the DEBRA Stroll
11.00pm	Close

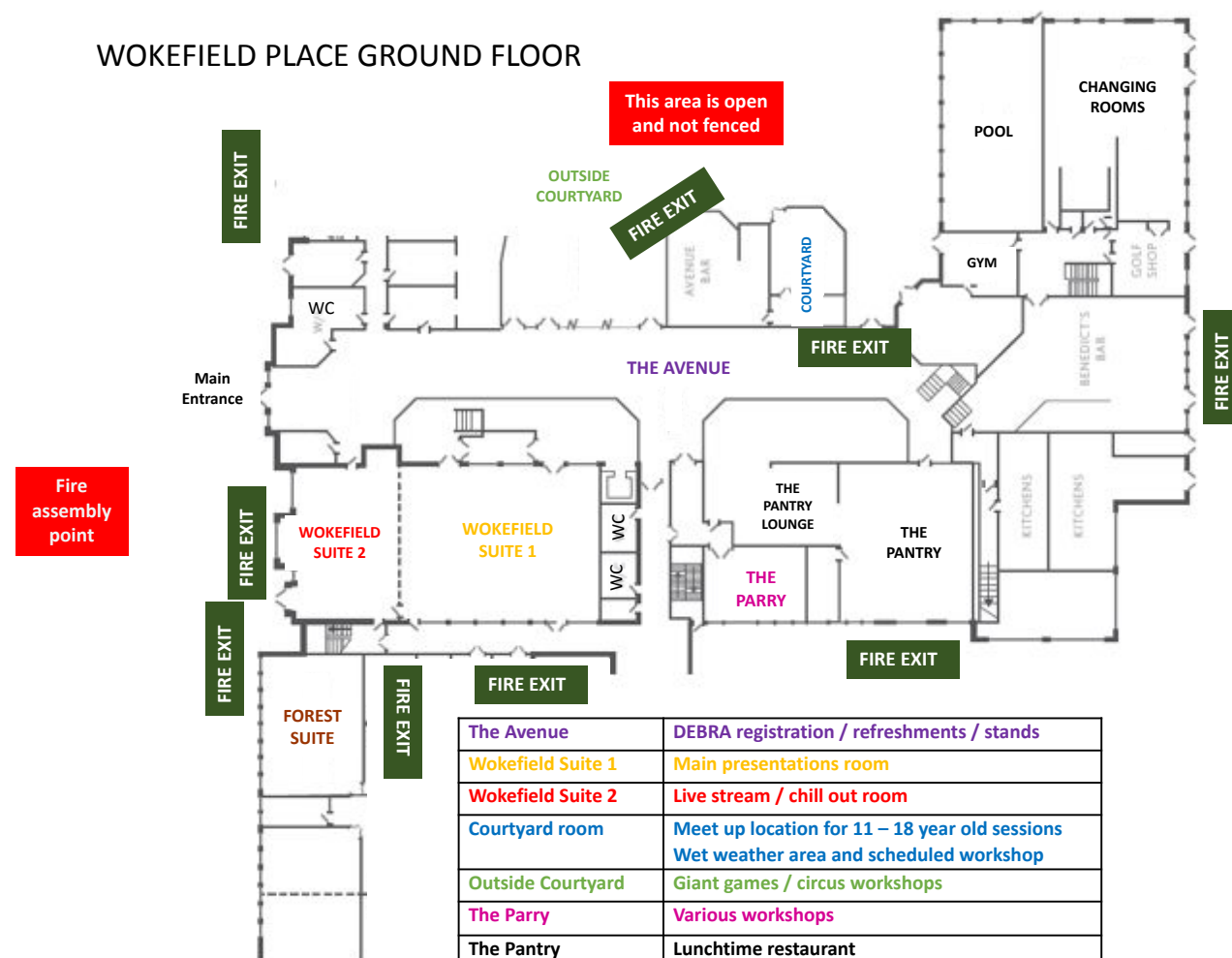
Sunday

7.30am – 10.30am	Breakfast is served in 'The View' Restaurant (1st floor)
11.00am	Latest bedroom check-out time

Please feel free to explore the lovely places nearby (for example Windsor or Wellington Country Park) and head home at your convenience.

*Evening dress code: Smart casual.

WOKEFIELD PLACE GROUND FLOOR



GENERAL INFORMATION



Hotel information

Bedrooms will not be available until 5.00pm. If you are staying overnight, you will be able to collect your room key after 5pm from the hotel reception.

For disposal of dressings, please pick up a black bag at reception as dressings cannot be put in hotel/bedroom bins (sharps must be taken home in your sharps bin).

The hotel is a cashless venue, please ensure you bring a card with you for any purchases you wish to make. Anything you add to your room you will pay for on departure.



Illness and COVID-19

We politely request that if you are not feeling well that you do not attend this event. In these circumstances we will refund any money that you have paid to us.



Internet

Open your Internet browser, type in any web address you require, and you will be taken to the De Vere Internet access web page. Then tick the terms and conditions box and submit.



Membership & Community Support Team

We are here to help. If there is anything you would like to talk about or ask, please go to the Community Support café area in the Avenue or visit the registration desk.



Refreshments

Drinks are available throughout the day from the refreshment areas in the Avenue.

If you wish to purchase any food and drink in addition to what DEBRA is providing, you can visit the Benedict bar during opening times. Crisps, chocolate, ice creams and drinks are available to purchase from reception.



Photography

A DEBRA photographer will be taking photos – these may be used by DEBRA UK to advertise events, promote our work and raise awareness of EB. We will be able to share these professional photos with you.

If you would like to opt out of being in photographs, please visit the DEBRA registration desk and we will do our best to exclude you from photographs. We also advise you to move away when photos are being taken or to alert the photographer to your preferences.

Please do not film or take photos of the presentations as information may be confidential and restricted.



Filming in the Wokefield suite

We will be filming presentations in Wokefield 1 suite. Please be aware that if you walk in front of a camera in the room you will be filmed.



Live-streaming and chill-out room

There will be live streaming into Wokefield 2 room, which is a chill out zone where you can view the live-streamed presentations. This is to help parents who may want to use this area with their children and will include a book area, activity sheets and timetabled craft activities.



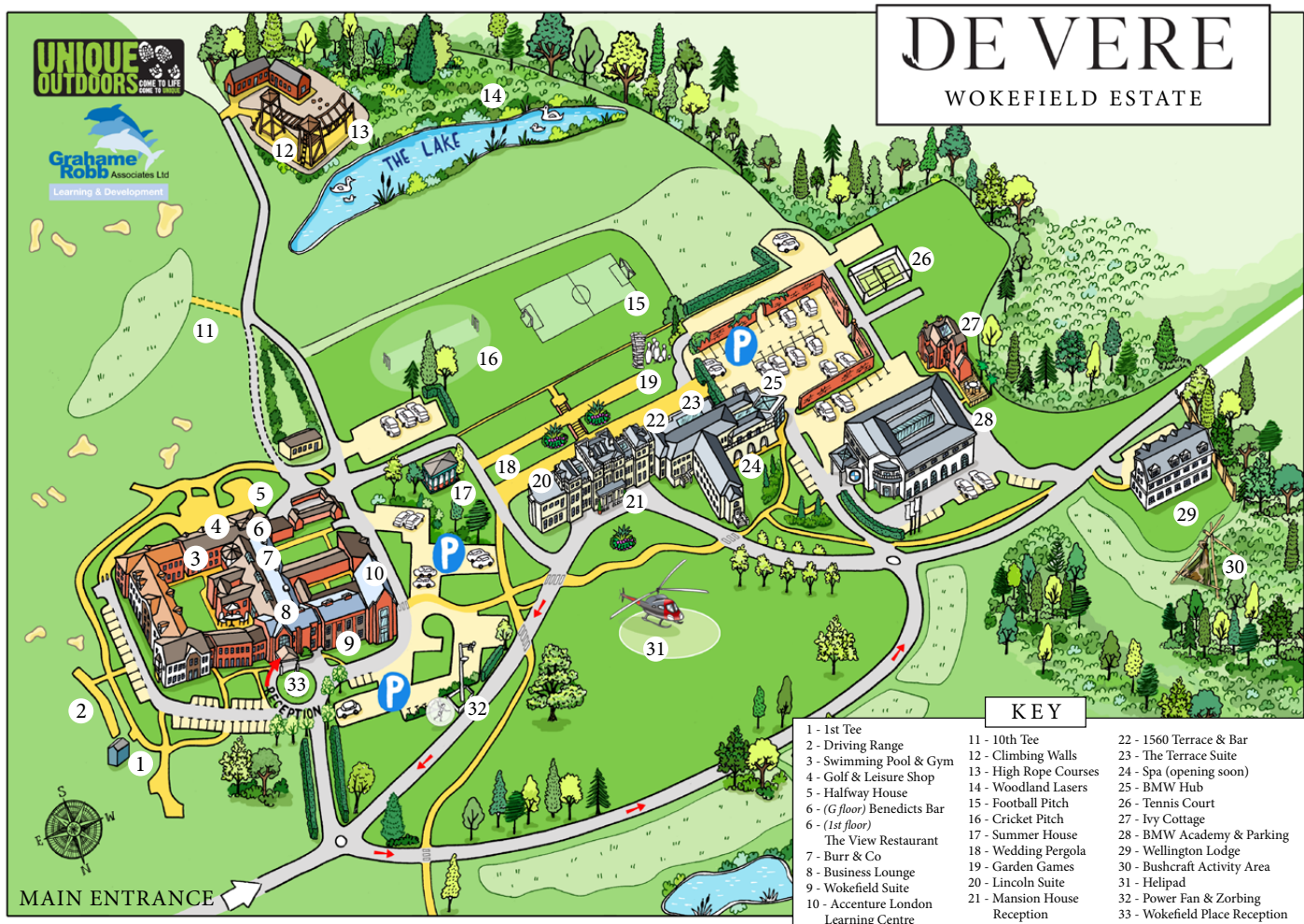
Other facilities

Ask at reception for dressing changes room and prayer room.



Lost property

Please ensure you take responsibility for personal belongings. Any lost property should be handed in to the hotel reception.



THANK YOU



Thank you to everyone who is involved with making this wonderful event happen. There are too many of you to mention individually, but we appreciate everyone's time, ideas, enthusiasm and most importantly commitment to make a difference to the EB Community.

Your feedback matters

It is really important that we receive your feedback and ideas to help shape future events and Member engagement. We will be gathering feedback during the day, in various different ways. Please also scan the QR code and feedback via our short survey.

