

# FRIENDS GROUP HANDBOOK



debra debra

**debra**  
for people whose  
skin doesn't work  
we do



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Congratulations, you're all set up! So now what? This booklet will give you a really good insight into fundraising activities you can utilise and how to keep everything legal. Every group will be different, so it's all about working out what is the best fit for you.



## OUR VISION

A world where no one suffers from the painful skin condition Epidermolysis Bullosa (EB)



## OUR MISSION

Provide lifelong care and support to everyone in the UK affected by EB



## OUR AIMS

Fund pioneering research for symptom alleviation and, ultimately, a cure

Provide care and support to the entire EB community



# THE DIFFERENCE YOU MAKE



1,630 EB patients supported in England and Wales



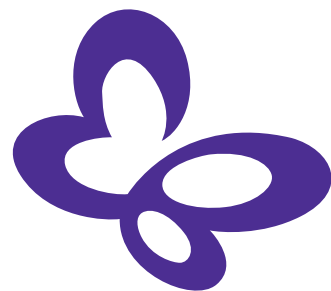
14 research projects facilitated



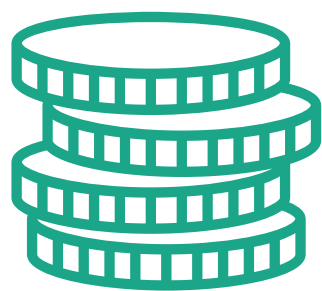
£866,000 spent on Membership and Community Support activities



2,892 DEBRA Members across the UK



51 DEBRA organisations worldwide



£958,000 committed to new research projects



422 home visits made



19 global EB research sites





# FUNDRAISING TO #FIGHTEB

## LAUNCH EVENT

Having an official launch as a Friends Group is the perfect way of introducing yourself to the community. There are plenty of different ways you can put on this event:



Gala dinner



Garden party



Tea party



Golf day



Bake sale



Quiz night

Or you could be inventive and come up with your own way of launching your group – the more creative, the better!

## PLANNING

Now that your group is launched and the local area knows about you, it's time to start planning the year ahead. We will work with you to come up with an agreeable target and set about achieving it!

## FUNDRAISING EVENTS

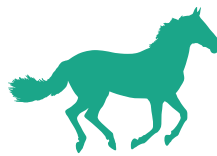
You may decide that the best way for your group to move forwards is by making a calendar of fundraising events. These could be any of the ones listed above, but can also include:



Spinathon



Sponsored run/walk



Race night

The sky is the limit when it comes to which events you decide to use and organise. It is really important to run a full risk assessment ahead of each event and to purchase your own event insurance (see appendices).

When planning an event it is really important to consider the following:

- Date – avoid clashing with any other big events on the same day
- Venue – it needs to be accessible to everyone and give you a great feeling but also be a good price so you can maximise fundraising return
- Selling the event – consider beforehand how and who you will sell to
- Ticket prices/entry fees – these need to be competitive but provide a good return. A general rule of thumb suggests the event costs should at least be covered by ticket price

- Sponsorship – any local businesses or contacts who might be interested. Think about attractive opportunities you could offer
- Fundraising activities – how will money actually be raised on the day? Will it be purely entry fees or will there be things like a raffle, tombola, auction or welcome game?

As with any of the information in this handbook, your dedicated DEBRA contact will be on hand to offer as much or as little support as you need in putting these events together.

## BUCKET COLLECTING

Heading out into your local community is a fantastic way of increasing your profile as a local group and combining with a bucket collection means you can be assured of a reasonable return on your time. Local supermarkets, shopping centres and sometimes sporting venues can be very accommodating to these requests. Your DEBRA contact will provide an example letter you can use when approaching them.





## MAKING YOURSELF KNOWN

Get in touch with existing local events and see if you can set up a stall and increase the profile of your Friends Group to the local area. You can talk about EB, DEBRA, the inspiration behind the group and also let them know how they can get involved (by joining a bucket collection, helping to distribute collection tins or attending one of your events). You may even wish to provide a fun, little game to attract people to your information table, e.g. hook a duck to win a donated prize or play Jellybean Roulette.

Local events could be:



Classic car shows



Music festivals



Local fairs and fetes

## LOCAL CLUBS

Rotaries, Masons, Lions Clubs, Inner Wheel Clubs, Roteracts...the list carries on! All are incredibly generous in providing support and by operating in the local area you have a distinct advantage in being able to leverage their support. Between 2014-2017, local clubs have donated over £190,000 to DEBRA. The appendices contains another example letter you may wish to use to approach. Groups can sometimes be keen on a charity representative coming to talk to the group – we are happy to provide any training or resources you need to prepare. An example list of clubs would include:



Rotary Clubs



Masons



Hobby Clubs/Sports Teams



Lions Clubs



Religious Groups



Scouts/Guides Groups

## COLLECTION TINS

Collection tins are a really easy fundraising technique. You're not personally asking for any money and for the business involved they just need to place a tin on the counter – and this can very quickly add up. DEBRA can receive over £10,000 a year just from collection tins alone. All you need to do is pop by a local shop or business and ask to place your tin on their counter and offer to collect it when full. Once a month you can make the journey to all of the places with a collection tin to collect the tin and offer them an empty one – we can make sure to provide you with enough to do this. Don't worry if they say no, there are plenty more places you can put one! An average local shop can bring in £100-150 a year with very little work required.



## LOCAL SCHOOLS

Engaging local schools is a fantastic way of not only fundraising but also teaching the next generation all about EB. The best approach to schools fundraising is by using existing networks – one great way of reaching out is offering materials to hold a butterfly hunt (DEBRA Head Office can supply these) followed by a short assembly on EB.

## UNIVERSITIES

We fully encourage you to explore any existing contacts you may have with local universities in the first instance. Raising and Giving (RAG) Societies are highly motivated student bodies that can mobilise large parts of the university population into raising funds and awareness. RAGs regularly raise over £10,000 per year. The most common time for applying to be a local RAG partner is between February and August but it is worth checking with your local university. Make sure to apply as a national partner but keep the application 'local based' with your inspiration for fundraising.

## EXISTING CONTACTS

One of the unique things you can bring as a new Friends Group is your contact network. It may well be that you have contacts at local businesses, golf clubs, schools or universities. We encourage you to explore these fully as these are already warm contacts and will likely provide you with the greatest chance for success.



## LOCAL BUSINESSES

These can make a big difference to your fundraising. We do ask you to let us know in advance any you wish to engage. It may be that we make the pitch together as there is potential for a fantastic corporate relationship, or we leave to you as you are best placed to make the ask.

## LOCAL SUPERMARKETS

Nearly every local supermarket will support a charity or charities throughout the year. For example Sainsburys have a charity of the year, but Waitrose support 3 charities each month through their Community Matters scheme. It is definitely worth checking each local supermarket (Tesco, Waitrose, Aldi, Lidl etc.) to know when you can apply and how often you can apply.

## NISA LOCAL

Nisa stores run a campaign called Making a Difference Locally. Under the model branded products featured on Nisa's consumer leaflet now contribute, carrying charitable donations from the supplier. This is in addition to the funds raised from sales of Nisa's Heritage own label products. Stores are able to donate funds raised to a local charity or good cause of their choice within a 10-mile radius. We encourage you to locate all of the Nisa stores within your area ([www.nisalocally.co.uk/stores](http://www.nisalocally.co.uk/stores)) and call in to see if they would be willing to support.

## SUPPORTING REGULARLY

A great opportunity to engage is by inviting potential supporters to sign up to the DEBRA Lottery, which includes a chance to win £25,000. At least 50p in every £1 comes to DEBRA and by having regular players allows us to plan for the future with greater certainty.

The preferred route for regular giving is by direct debit. We will receive 100% of the donation and potentially a further 25% if the donor chooses to use the Gift Aid scheme. A great way of selling this is that for the price of a weekly coffee (£2.50), you can help an EB sufferer for an entire day through healthcare, membership and community support.

## GIFT AID

Encouraging your supporters and donors to Gift Aid their donations (if they are a UK taxpayer) means that DEBRA can reclaim the tax on the donation (25%). A sample gift aid form will be sent to you by your DEBRA contact.

## MATCHED FUNDING

A large number of employers will match fund charitable efforts – it is always worth exploring this at your work place and encouraging anyone who has attended or helped at an event to do the same. An example list of a few places which offer this can be found at <https://wilsonspfa.org/fundraising/matched-funding>.

## LEAVING A GIFT

Leaving a gift in your Will is a simple way to fight EB - it can be included as part of your financial planning and we recognise that your loved ones come first in your Will. Head to [www.debra.org.uk/leaveagift](http://www.debra.org.uk/leaveagift) for more information.

## WHEN TO INTRODUCE

Whilst we will fully support you in your fundraising, we do ask that you pass over any key contacts you make with potential major donors, national businesses, high value trusts and foundations or celebrities/high profile individuals so that we can manage this relationship.





# MARKETING

The media is a hugely important tool for raising awareness of EB and supporting your fundraising. Thousands of people read their local papers and millions of people in Britain watch TV every day.

We definitely encourage you to use the media to raise the profile of your Friends Group, but follow the procedures below to make sure you get your message across clearly.

## POWER OF THE MEDIA

The media is a hugely important vehicle for fund and awareness raising. For example, DEBRA has recently had articles published in Chat magazine which has a weekly circulation of around 331,000.

## SOCIAL MEDIA

Set up Facebook, Twitter and Instagram accounts to share updates and stories about your Friends Group and raise awareness of EB. Link back to our accounts so your audiences are introduced to DEBRA directly too. And remember, unless your Facebook group is a closed group or your tweets are protected, all the information, pictures and links you share will be in the public domain!

## WEBSITE

As promised in our agreement we will also provide you with your own page on our website. We'll always have an updated fundraising total for the group and a donate option, but the rest is your free space to use (e.g. it could be used to help promote your upcoming activities) and tell your story. We recommend setting up a bespoke email just for the group so that this can go on the page, e.g. locationfriends@domain.com. An example Friends Groups page can be seen by visiting: [www.debra.org.uk/fundraise-for-us/example-friends-of-debra](http://www.debra.org.uk/fundraise-for-us/example-friends-of-debra)

## TALKING TO LOCAL PRESS

Local press is absolutely vital to raising the profile of EB and the work of your local group. Your contact will send you an example press release document and some tips on how to introduce yourself to local media. Inviting them to a launch event is a perfect opportunity to start the relationship.

## TALKING TO NATIONAL PRESS

If you are approached by national media then please do get in contact with your DEBRA Contact - it's really important that we present a united message. Similarly if we receive any national media requests and believe you would be the perfect fit for interview, we will get in touch.

# BRANDING, MATERIALS AND DESIGN

DEBRA will provide you with your own bespoke 'Friends of' logo, along with branded letter head and banner roll using this bespoke logo. We do ask that if you are planning on producing any documents for the group to please get in contact with your DEBRA Contact first. As with the national press, it is important that we are able to provide consistent messaging. As time progresses and if targets are met then we can certainly look at producing bespoke leaflets and other items. This will be done on a case by case basis.

## #FIGHTEB

Wherever possible please push the promotion of fighting EB! It's a very strong part of our message and very easy to use – e.g. we are fundraising to fight EB, or thank you for attending our event, your support is vital to fight EB.







# BANKING AND FINANCE

The following information is really important for the safe running of your group, and to ensure all of your fundraising activities remain accountable and robust against any potential scrutiny.

## PAYING MONEY IN

DEBRA will issue the group with bank giro credits which will allow easy deposits into our HSBC account. Monies can also be transferred via online transfer (HSBC, 41132547, 40-18-46), sent via post (we do not recommend this for large cash amounts), or online using JustGiving/Virgin Money Giving as outlined below.

We ask that you inform us of all money being paid into our accounts for your group so that we can attribute this correctly.

## JUSTGIVING/VIRGIN MONEY GIVING

We will create a dedicated account page for the group using DEBRA's main JustGiving/Virgin Money Giving account. This will enable fundraisers to create online pages to support your group with ease and allows you to keep track of all funds raised as this account page will be regularly updated by the team to include offline amounts. An example page can be found here: [www.justgiving.com/campaigns/charity/debra/londonmarathon2019](http://www.justgiving.com/campaigns/charity/debra/londonmarathon2019).

## MONEY HANDLING POLICY

The government's money handling policy states that there should always be two individuals counting money. Both must sign the form to witness the amount collected. This form must then be returned to Head Office or a DEBRA representative. This should be sent with the fundraised amount, unless this is to be paid in via bank transfer, bank deposit or online via JustGiving/Virgin Money Giving.

## TREASURER

We ask that each group nominates one dedicated person as a Treasurer, or the money payer. This ensures that all contact regarding amounts remains with one person and saves any potential confusion if multiple sources quote the same amount. The Treasurer is also responsible for the following:

- Providing a full account for all money raised at each fundraising activity
- Recording financial transactions

## STAYING SAFE

- Try not to leave money unattended
- Bank the cash as soon as possible to ensure it is not on your persons for an extended period
- If threatened for the money, hand it over and report the theft to the police and DEBRA



# APPENDICES

## RISK ASSESSMENTS

A risk assessment is a requirement before your event can be insured, and it gives the chance to think ahead and minimise any potential risks and dangers for guests. Four steps to an effective Risk Assessment

### Step 1. Look for the hazards

A hazard is anything with the potential to cause injury or damage. At this point don't think about how serious or trivial the hazard is, just list everything you think could potentially go wrong.

### Step 2. Decide who might be harmed, and how

Once you've identified your hazards, think about who and what might be harmed and note down your thoughts.

### Step 3. Evaluate the level of risk

Risk is the chance, big or small, of harm actually being done. Use the risk matrix below to assess how serious the risk is by deciding how likely it is to happen, how serious it could be if it did and whether you need to take any further precautions:

#### Risk Matrix

##### Potential for harm or damage

CHANCE OF THIS HAPPENING	INSIGNIFICANT	MINOR	MODERATE	MAJOR	CATASTROPHIC
High	1	2	2	3	3
Medium	1	2	2	2	3
Low	1	1	1	2	2

For example:

Hazard: Volunteers being scalded or burned whilst using a hot water urn  
Likelihood of it happening: Medium  
Potential for harm or damage: Moderate  
Risk factor: 2 – medium risk; worth taking preventative measures.

### Step 4. Record the significant hazards and identify what measures you could take to eliminate or reduce the risk

- There are many ways to reduce risk but they largely boil down to the following:
- a) Providing information/training. Signs, information sheets, training and, if necessary, consent or waiver forms can all reduce risk.
  - b) Taking physical measures. Consider changing the way you do the activity, for example by using safety equipment, increasing supervision etc
  - c) Cancelling the activity. If an activity is too dangerous even with training and changing the way the activity will work, then don't do it.

Use DEBRA's risk assessment form to note your conclusions (see example below). For each hazard, assign a new risk level for the activity once the safety measures have been put in place. If an activity remains high risk even with safety measures in place, then don't do it. In the case of the safety urn, it is considered that applying the suggested safety measures would bring it down to an acceptably low risk.

#### Example Risk Assessment

THE HAZARDS	CURRENT RISK MATRIX	CONTROL MEASURES	NEW RISK MATRIX
Hot water urn:  Potential for scalding and or burning if urn is knocked, bumped into, or improperly operated; or if operator is knocked or bumped into whilst using it.	2	Urn to be kept away from public  Operated only by 2 volunteers  Warning sign on urn	1

Name of Event or Activity:  
Date of Event or Activity:

Risk Matrix						
CHANCE OF THIS HAPPENING	POTENTIAL FOR HARM OR DAMAGE					
		Insignificant	Minor	Moderate	Major	Catastrophic
	High	1	2	2	3	3
	Medium	1	2	2	2	3
Low		1	1	1	2	2







As a fundraising volunteer you may collect people's personal data, for example names, addresses and email addresses. There is a requirement to keep this data safe and DEBRA must comply with the GDPR requirements and has policies that cover how this data is stored and processed. It is imperative that any Friends Group acting on DEBRA's behalf maintains the same high standards when it comes to data protection regulations.

Personal data stored in a paper file or an excel spreadsheet or any other written record must be kept securely in a lockable or password protected filing system.

For example, if you are organising a ticketed event you may have to send tickets to addresses or if you create a newsletter you may keep people's addresses or email addresses. These must be securely destroyed once the purpose comes to an end.

When sending to more than one email address please use the Blind Carbon Copy (BCC) email address option for your email list. This will hide the email addresses from each individual.

Personal data should not be shared without the explicit permission of the owner of that data.

If you believe that any of your stored data has been seen by an unauthorised third party, this is a data breach. All suspected data breaches must be reported to DEBRA immediately.

## Privacy Policy

We respect the privacy of all who come in contact with DEBRA will not pass details on to any third party without permission. Should any supporters ask how we will be using their data, please do direct them to [www.debra.org.uk/privacy](http://www.debra.org.uk/privacy).

## Tips with Data

- You must use the data fairly, i.e. only use it for the purpose that you collected it for unless otherwise stated by the individual. Be honest and upfront about why you want the data
- Be really vigilant about keeping data safe. Don't leave documents with personal information lying about and be careful about using these in public. Similarly if using data on a mobile device be cautious about who is around and can see your screen. Make sure to use password protected files or use an encrypted hard drive to store data so that in case of a stolen device the thief can't access personal and sensitive data
- Don't collect unnecessary data. If you are organising a gala dinner then knowing an attendee's age isn't relevant and nor is knowing emergency contact details. Similarly if you are organising a run, you don't need to know a participant's dietary requirements
- Regularly update your records. If someone no longer wants to hear from you or if you have lost contact with them then their data should be deleted. We recommend checking your stored information once a year
- Don't pass on any details to any other organisations unless you have consent or it is needed to prevent serious harm to an individual or can be used in crime detection
- The team will always be on hand to answer any questions you may have if you're not sure on an answer

A really good way of considering the new data protection rules is how would you want your own data to be used?

## Data Sharing Agreement

As we may be sharing data with each other from time to time, e.g. a supporter approaches you but you believe the relationship is more beneficial with the DEBRA Team, or someone approaches head office about getting involved specifically with your group, we will need to both complete a data sharing agreement.

## SAFEGUARDING

DEBRA is committed to promoting the welfare of, and safeguarding, all children, young people and vulnerable adults with whom we come into contact during our work.

We believe that all children, young people and vulnerable adults have an equal right to protection from abuse, regardless of their age, race, religion, ability, gender, language, background or sexual identity; we consider the welfare of the child, young person or vulnerable adult to be of paramount importance.

We will take every reasonable step to ensure that children, young people and vulnerable adults are protected in our working environment and that beneficiaries of DEBRA are protected whilst being supported by the charity.

All reported allegations of abuse will be taken seriously, investigated thoroughly and appropriately reported by trained personnel, recognising the sensitivity of safeguarding issues as well as the importance of confidentiality and data protection.

We commit to ensuring that all employees and trustees are sufficiently informed about safeguarding to speak up and report suspicions of abuse, and we expect all employees, trustees as well as any volunteers who have supervisory responsibilities to have read, understood and adhere to this policy and related procedures.

As part of our commitment to Safeguarding, we will be providing DBS checks for the main contacts within our Friends Groups. If you have witnessed a potential safeguarding concern that needs addressing, please report this to your DEBRA contact immediately. If the concern is regarding your DEBRA Contact please contact Louise Westphalen, Director of Human Resources, on 01344 771961.



### Health & Safety

It may sound simple, but please be careful! Fundraising should be an enjoyable, social activity but it is of paramount importance to keep yourself safe and protected at all times.

- Try to work in pairs if possible
- When collecting and storing money keep yourself as safe as possible e.g. walk on well-lit streets etc.

### First Aid

Your event may need a First Aider on site if there are over 50 guests in attendance – check with your local authority for guidance on this. Most events venues will have trained First Aiders on site throughout your event.

For First Aid options, St. John's Ambulance and the British Red Cross provide competitive prices.

### Risk Assessment

As said before, a risk assessment is vital before holding an event. It gives the chance to think ahead and minimise any potential risks and dangers for guests, and is an insurance requirement.

### Food Safety

Food hygiene laws apply at all times when food is involved, regardless of whether it is on sale or not. For advice, please check the Food Standards Agency website.

The Institute of Fundraising Safety and Safeguarding pages at [www.institute-of-fundraising.org.uk/guidance/safety-and-safeguarding-in-fundraising](http://www.institute-of-fundraising.org.uk/guidance/safety-and-safeguarding-in-fundraising) can also be a fantastic resource.

### Gift Aid

The Gift Aid scheme is a fantastic way of ensuring that donations can go further; however there are a few restrictions. It can only be claimed if:

- The donor is a UK tax payer
- When filling out a paper form, all details must be filled in by the individual wishing to use the Gift Aid scheme
- No item is being received in return e.g. an entry into a race, event or raffle; or when paying for an auction item

Please send us all completed Gift Aid forms; the forms should clearly state the amount donated and the event/reason the donation has been made.

### Public Collections

If you are looking to hold a public collection you must have permission from the private land owner (i.e. supermarket or shopping centre) or from the council if you wish to collect in the streets. It is a legal requirement that you do not shake your bucket and the public must not feel pressured to donate. If in doubt, please ask your DEBRA contact.

### Licences

You will need a licence if you plan to do any of the following:

- Hold a raffle that begins and ends on different days (a raffle licence can be obtained from [www.gamblingcommission.gov.uk](http://www.gamblingcommission.gov.uk))
- Raffle drawn at a different location to the location of ticket sales

### Temporary Event Notices (TEN)

On occasions you may need to apply for a TEN for one of your events. These can be obtained from your local council and will cost £21. You should apply for one of these if:

- Selling alcohol (if no alcohol licence at the venue)
- Serving alcohol to members of a private club
- Providing entertainment, such as music, dancing or indoor sporting events
- Serving hot food or drink between 11pm and 5am

For more detail please check your local council's website.

### Charity Number

It is a legal requirement to include DEBRA's charity number on any promotional materials including flyers and event programmes. The wording can be anywhere on the document and should read:

**DEBRA is a charity registered in England and Wales (1084958) and Scotland (SC039654). Company limited by guarantee registered in England and Wales (4118259).**

### Insurance

Whilst DEBRA's Public Liability Insurance will cover you for cheque collecting, holding small scale events such as a bake sale or distributing collection tins, it will not cover you for holding larger events, such as organised runs, cycles or gala dinners. It is important that you take out event insurance to cover yourself and for peace of mind. Most insurers will require a risk assessment for the event. If in doubt, please ask your DEBRA contact.

### Fundraising Regulator

DEBRA is registered with the Fundraising Regulator and is committed to both the Code of Fundraising Practice and Fundraising Promise. More information can be found at [www.fundraisingregulator.org.uk](http://www.fundraisingregulator.org.uk).





# YOU ARE A FUNDRAISING HERO

 /DEBRACHarity  @CharityDEBRA  charitydebra

DEBRA is a charity registered in England and Wales (1084958) and Scotland (SC039654).  
Company limited by guarantee registered in England and Wales (4118259).

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