Judith Hutton is the grandmother of a teenage boy who was born with EB, a genetic disorder similar to PC. Over the years she has raised thousands for EB research. Her enthusiastic approach will motivate you to do whatever you can to further research for PC.

She has kindly allowed us to post the notes from her talk.
It is a great pleasure for me to meet you all and I have enjoyed the informative talks and the fellowship engendered very much. There are some fortunate people in this world who have no health problems and I strongly feel that those of us who have relatively little to complain about could put our energy into doing what we can to help those, who through no fault of their own, have difficulties one way or another. Not only can it help to ease their burdens and enhance their lives a bit but it serves to take our minds off ourselves.

My remit is Fund Raising and there are levels of this. I guess it could be summed up in one sentence. "He who whispers down a well about the goods he has to sell will never make as many dollars as he who climbs a pole and hollers!" There are the big names – stars of film, TV, radio and politicians well known to us all (in fact the president of DEBRA is Michael Portillo who works very hard on Debra’s behalf). These people have many connections and are capable of organising massive functions in prestigious venues – charity lunches, dinners and balls for hundreds of people which raise unbelievable sums of money. Then there are the sports occasions – golf competitions, tennis matches, fishing days, sponsored walks, cycle runs, swims etc. Not all of us can do this or are brave enough to try! The next step for more ordinary mortals is approaching Trusts, cinema shows, auction of promises, marathons, triathlons, quiz nights, race nights, whisky or wine tasting evenings, home dinner parties and even daffodil teas! My Fund Raising was very much at the grass roots – the kind of thing anybody can do
and although I played such a modest role for DEBRA if even one person goes home with one idea from what I did, it will be worthwhile.

It is said ‘charity begins at home’ – well, I guess it does. Certainly I was jolted out of my complacency when my beloved grandson, David, was born sixteen years ago and I first woke up to the enormous need to fund the all important research which was the best way forward. In any misfortune people can sit in a corner wringing their hands and weeping which of course is a downward spiral or they can get off their bottoms, roll up their sleeves and get on with doing whatever is required to raise funds. Most families have some relatives who could surely help in some way.

So what could a very ordinary 58 year old Granny do to lay her hands on cash. I began by finding out all I could about the disorder and the charity and I had DEBRA send me whatever publicity they produced - posters, explanatory leaflets etc. and I made up a short presentation talk and went round speaking to any group that would listen – Rotary and Inner Wheel Clubs, Lions Clubs, WRI, Church Guilds, Schools and the like. I chose those only a reasonable travelling distance from home. People said ‘Oh, I couldn’t get up and speak in public’. Nonsense! When there is something very close to your heart you can pretty well do anything – if you try!

Another successful area I tried was a can collection at the famous Murrayfield Rugby Stadium but any football or
sports stadium would serve the same purpose. A permit from Edinburgh District Council had to be obtained and the designated number of collectors, armed with cans or buckets and wearing tabards emblazoned with the charity name can fill the cans in no time at all. This would also apply outside supermarkets or large stores.

While all this was going on I managed to persuade the minister of our church that what he needed was to hold a Christmas Fair! - selling charity Xmas cards and gifts. When I eventually wore the poor man down, I chose the first Saturday in November when lots of people still had Xmas shopping to do. I invited eleven other charities to join me with their stock and to display their wares on 6’x3’ tables. Help come from everywhere and the Scout Group helped with the heaving of numerous cardboard boxes.

Because I was keen for the sale to be a happy social occasion too, I arranged for tea, coffee and biscuits to be served all day with soup and filled rolls over the lunch time period. The cash and carry were willing to accommodate my needs and the nearest Safeway store generously gave me 12 dozen rolls free of charge. In my own kitchen I made soup and 900 ginger snaps and lots of my chums rallied round making gallons of ever so tasty lentil soup which was very welcome on a cold winters day. A team of family and friends filled rolls, dispensed tea and coffee throughout the day, washed and tidied up. There was a real buzz about the place and lots of lonely people were there for several most of the day! I was overwhelmed and not a little humbled by the support of the occasion.
I set up a DEBRA baking stall headed by a wonderful friend who is a fantastic baker and who requested (bullied) everyone she knew into contributing masses of delicious goodies. My daughter and I made chutney, marmalade and jam until we had no jars left.

My husband manned the Gardening stall and clematis plants and the like arrived in tray loads. I visited a wholesale flower market and they allowed me to buy (at greatly favourable prices) beautiful African Violet and Primula plants etc. Also some seasonal silk poinsettia bunches and silk red roses and a few buckets full of magnificent carnations which not only looked welcoming but gave off a delightful scent.

My husband was retired by this time and he is a bit of a handy man so he set to and made small picture frames, wastepaper bins, bird boxes, garden trolleys for moving plants around, footstools, tip up stools, toilet roll stands, banana stands, tea pot & casserole stands, small rocking horses and 400 lap trays (which sold at £10 each) and anything else that he could think of.

I undertook to produce all the soft goods and to provide the articles for the main stall. I had to get help with the knitting section as no one would buy what I knitted! I found that there were lots of willing ladies who enjoy knitting or crocheting of an evening in front of the TV as long as it was baby things. So they produced various sizes and colours of baby jackets, scarves, hats and bootees,
knitted fun dolls, tea cosies, cot and pram blankets, Xmas tree hangings and even bed socks! All of which sold very well.

I sewed —virtually non stop. I obtained material from shop sales, at markets, charity shops and sample books and off cuts from local curtain makers which were invaluable for making peg bags, hot water bottle covers tea cosies, cafetiere covers, pot holders and shopping bags. Then there were cushions, neck cushions, pot pourri bags, shoe bags, baby cot and pram quilts, bean bags, covered padded coat hangers, draught excluders, door stops and stuffed animals. The Xmas range consisted of Xmas stockings large and small, wall hangings, table cloths and napkins, table mats, table centres, tree skirts, advent calendars, Xmas bells and bows and anything else we could think of. And of course the DEBRA Xmas cards.

In order to have plenty of variety I selected factories making high quality goods which would be suitable for my kind of sale. It was essential that I only provided top quality. I wanted customers to return year after year. On the whole I was well received and obtained generous discounts in many places. In this way I found lovely soap, bath salts, shampoo and the like. At another outlet I bought luxury face cloths, hand towels, oven gloves etc. I bought candles, leather purses and address books (never diaries or calendars). I had beautiful handkerchiefs sent up from the Midlands for ladies and men and also for the men I found leather belts and silk ties. There is a factory who sold melamine trays of various sizes and a lady who sold
me luxury boxes, wrapping paper and paper napkins. Almost every Saturday from my big sale until Christmas there were sales in neighbouring churches at which I took a table and so the money rolled in. Monie a mickle maks a muckle!

I was immensely indebted to all these generous suppliers and to the local haberdashery firm who supplied me with thread, pins, bindings and tape. There are lots of people of good will around and I met many of them. Our lives became a full time voluntary production line and as a family, we managed to raise enough money to pay for at least one research project.

Another important aspect if Publicity. Your sales have to be well promoted and the publicity has to be really strong and very visible. I roped in a relative who had a connection with and advertising agency and this impressive poster was created and laminated. I climbed up a ladder and tied them up on lamp posts with plastic tags throughout the surrounding area. Nowadays, with health and safety and lots of the hide bound bits of legislation that have to be obeyed, it may be prudent to make enquiries in the regard before proceeding. I didn’t get caught! The local shop keepers and pubs kindly displayed my posters two weeks prior to the sales and local churches publicised it in their newsletters and notice boards. Friends — oh yes, I still have some! — displayed posters of the sale on their car windows and the local newspaper and radio station gave us a plug. I printed off some reminder notices and handed out bundles
of them for distribution. I wasn’t actually aware of anyone avoiding me in the street, but who knows or cares actually!!

I have been retired from the job now for a number of years but I am still in receipt of money for DEBRA from a public house who holds a New Year Charity party for us which raises about £800 annually and also from a man who collects aluminium cans and a newsagent who keeps a collection can on his counter.

This, then, is what can be done at the grass roots by an ordinary family and if we can do it anybody can. I’d like to finish by reading you this little poem.

It is called The Rose.
Supposing, just supposing that one petal of a rose said “Nobody will miss me, I could fall off if I chose. I really need not bother to flush my petal edge, or fill my heart with perfume, or keep my beauty pledge and smooth my satin garment that the dew this morning kissed. There are many other petals that just one could not be missed. Then another petal of the rose would murmur with a sigh “That petal isn’t bothering, then why indeed, should I?” While another and another would follow suit you see, and what a dreadful withering thing our lovely rose would be. So its working all together in harmony of soul – every unit gives its best to make the perfect whole.