

CHAIRMAN'S REMARKS

I would like to welcome everyone once again to the city of Perth for our AGM.

Our thanks to Dr Burns for giving up her time, coming along to our AGM and giving us such an interesting presentation.

Another year has gone and here we are at another, AGM our sixth as the Scottish Association. It seems no time at all since we set up yet here we are approaching the start of our seventh year, let's hope the next six years are as successful as the previous six have been.

CHAIRMAN'S REPORT

At last year's AGM there was active discussion on the future of the SACHD and it was decided this theme would be taken forward to be discussed at open committee meetings throughout the year. Discussions have been and are ongoing at the meetings, Branch representatives and in some cases members have come along to discuss the issue, people have their own ideas and thoughts for the future but as yet there has been no clear view agreed or laid out. I have said previously the future of the Association will not be decided overnight it will take input from the members and will need people to be committed to the charity.

One thing that has come out of the discussions is the realisation that our web-site needs to be upgraded; it is felt the current site is tired and badly needs a facelift. The committee has enlisted the aid of a few members to form a sub-committee to move this on, they will report back to the next management meeting and hopefully the web-site will then be brought up to speed. But and I say this every year we need members and branches to send regular updates on activities no matter how small to the administrator to allow the web-site to stay up to date with all that goes on in the Association

I mentioned last year with numbers falling the committee agreed after much discussion to use S.N.I.P. (Special Needs Information Point) a charity based in the RHSC Edinburgh on a six-month trial to promote the Association to families attending clinics etc. SNIP will inform families of our existence referring them to us if they want or need family/parental support. This trial has been ongoing and we await a full report from SNIP but as yet I believe we have had no direct contact from families through SNIP.

I believe the Charity will continue as a support group offering support to new parents through our knowledge and experience as parents who have come through harrowing times but the Association like any organisation needs new members to continue to function and to evolve into the support group needed by families in this ever-changing world we live in.

Whilst talking about the future I feel it is appropriate at this point to mention Bravehearts group; earlier in the year Mark Maguire stood down as chair due to other commitments. We would like to record our thanks to Mark who over the years worked hard in the best interests of his fellow GUCH's fighting to improve services available through the NHS, attending meetings with clinicians and politicians to ensure they understood what he and his fellow patients not only needed but required. Thanks Mark and our best wishes for the future. Thankfully the lifeline in Bravehearts is strong and I can welcome on board a new committee chaired by Gill Mitan. Gill and her committee have taken up the challenge of dealing with the NHS to ensure the service on offer is the best that can be given.

The RHSC at Yorkhill is planned to close and the service moved to the Southern General campus in a tri-location with Adult and Maternity hospitals. The plan is for the new hospital to open in 2015.

The Association has been attending meetings with Greater Glasgow and Clyde Health Board and with other interested charities over the past few months keeping up with progress and discussing what charitable fundraising will take place on the run up to the opening.

I have brought along a few items from the meetings which I placed out on the table; I hope you managed to have a short read at them. Please do not take them away as these are my only copies, should you want a copy please let me know and I will order them. I attended a presentation and fly through from Brookfield the architects and it seems every idea put forward from user groups has been considered in the planning of the hospital.

We will continue to attend these meetings and keep members up to date with progress through the web-site.

The Glasgow Branch has recently completed a DVD of a "year in the life of the Branch". I have brought along a draft copy of the DVD, it runs for approximately 11 minutes and if you want to see it I can run it at the end of the AGM. The DVD will be made available to Branches to pass out to members old and new. It will also be made available to hospitals and clinics throughout Scotland asking them to pass it on to newly diagnosed families. We hope this will encourage new families to get involved in the SACHD bringing in new blood and in the long term ensure the future of the Association.

In terms of finance we have had a successful year, although income is down and the bank interest rate is low or non-existent we are once again holding our own: Willie will give details in his report later. We have had no major funding requests this year from the hospitals or clinics which mean our finances are perhaps stronger than they would otherwise be. We have recently received a couple of funding requests from RHSC Yorkhill but even if these are approved we will still be in a secure position.

Over the years the Association has run weekend breaks for families, teenagers and the Bravehearts group.

Sadly this year there will not be a Bravehearts or a teenage weekend. I am sure they will both start up again in the coming year as we have a volunteer to take over the teenage weekend and the new Bravehearts committee will organise theirs.

Once again in May this year we had the family weekend which as usual was at the Atholl Centre in Pitlochry. There was a good attendance at this year's weekend with 23 individuals coming along and having a ball. We had two new families and they have both said they will be back and with more of the family in tow next year. Thanks go to Kieran Wardrop the event organiser, Kieran put in a lot of hard work and effort to ensure everyone had a great time and were not disappointed with the accommodation, the bikes, the rowing, the swimming yes and even the weather. There is a report on the weekend on our website.

As you all know the Association has a caravan at Faskally outside Pitlochry and there is a board in the room showing availability of the caravan for the remainder of the year, if anyone is interested in making a booking please speak to Sandra Parkins who will be able to confirm the arrangements. Our thanks go to the Parkins family for running the caravan on our behalf.

As at every AGM I have to mention Christmas cards; Sandra has been unable to bring samples as she has not received the cards from the supplier. Our thanks go to Jeanette Forsythe and Elaine Wardrop for giving their time in early January to choose and order the cards for the coming Christmas, almost a year away. Last Christmas sales were steady and although we did not sell out the stock levels of 2009 cards are low. We still have a lot of old cards in stock, between Edinburgh and Glasgow we have about 1500 packs and we do not know if there are old cards with other branches so the number could be higher. We need every branch to try and sell off some of these to spread the load. We cannot thank Sandra enough for taking this on year after year, it is a lot of hard work and when the delivery is wrong Sandra has the hassle of sorting it out with the card company; many thanks Sandra, Brian, Tim and the girls.

I would like to say a special thanks to Liz d'agostino for all her hard work over the years; Liz has decided to stand down as secretary after a long number of years in the position. It is no easy task being secretary but Liz carried the job out to a high standard giving her best efforts ensuring minutes and agendas were out in time, writing the many letters required and keeping on top of things throughout. My very best wishes go to Liz, who for the first time has been unable to attend today. I am hopeful there is someone here today who feels they can take on this important position.

Finally I would like to thank my fellow trustee's for all the hard work they have put in to ensure the smooth running of the charity. I would like to thank all the branch committee's and their representative's who come along to the Scottish committee meetings without this the charity could not work. Thanks to Willie Gunn for his work as treasurer and for the financial reports. Thanks to Scott our Vice Chair and thanks to Jim Kelman for organising today's venue and last but not least to each and every-one of you for coming to today's AGM.

John Fegan
Chairman
June 26th 2010