

CHAIRMAN'S REPORT JUNE 2018

One again I would like to welcome all of you to this year's AGM, it is a pleasure to see everyone.

Our thanks to Dr Ruth McGowan and Eamon Murtagh for coming along today and giving us such an interesting insight to the "Joint Clinics Dr. Karen McLeod and Dr. Ruth McGowan set up in 2016 with our help. Dr. McLeod was called into the hospital and could not make it to the meeting.

The past year has been a sad one for a number of long term members as we lost a dear friend, Joyce Bruce. Joyce will be remembered as a happy friendly person who ran the branch in Aberdeen then set up the Banff and Buchan group, Joyce was chair of the Scottish for a number of years and will be missed by the charity. Donna will keep the branch going offering a contact for people in the area.

Our new additions to the position of Vice Chair and Trustee, Caroline and Lesley have now had their first year in post, both have settled into their positions. I am sure in the coming year they will feel better for the past year and have the confidence to help take the charity forward.

Our involvement with the Scottish Congenital Cardiac Service continues with our position on the advisory board. The standards for congenital cardiac care were partially launched during the course of the year. When I say partially that is to say they were split into the standards controlled by the NHS NSD who fund the Golden Jubilee and Royal Children's Hospitals and the standards that need to be implemented throughout all of Scotland's health boards.

The standards that apply to care in both hospitals have been launched and are in use (they can be seen on the hospital's website): the standards for the rest of the country have been referred to Health Improvement Scotland (HIS). HIS will carry out a 6 month scoping exercise which they are in the process of at this time. We have been invited to send a representative to a scoping meeting on the 7th September in Glasgow and a final meeting in December. In between the two meetings there will be email communication and if required further meetings. We have only one representative as do the TSF so if anyone has a particular interest in helping to ensure the standards are the best for all congenital cardiac patients please speak to me before leaving today. The scoping exercise needs to represent all our families views so when our representative emails out for views etc please respond so your views are included.

The Charity continues to support the clinical team at the New Children's Hospital, to this end we have provided 17 CoaguChek INRange meters to Lyn Docherty in Haematology who has taken over from Aileen Gibson caring for Cardiac patients on anticoagulation Warfarin treatment. We continue to provide Meters to grown up heart patients who are referred to us by the clinicians looking after them, providing they are deemed suitable to use a meter, as not all patients are.

The play equipment for the roof garden will be constructed and in place during the first week of July, at long last although the roof garden will close at the beginning of August for maintenance. It will give approximately 4 weeks of use prior to closing. The artwork in the Gatewell corridor where children do their walk test and the artwork in cardiology have been completed. These projects were funded by us through the fundraising efforts of Laura Shields, a grown up congenital heart who wanted to donate some money to spend on making a hospital visit a little less daunting and perhaps more fun. There are some photos of both Cardiology and the Gatewell corridor on the display board, if you have not seen them they are worth a look.

We also funded a Teenage video through What Why Children in Hospital, giving a teenagers view of living with a heart condition. If you have not seen the video and you would like to, then please visit WWCIH website where that along with many other videos are available to view.

The family weekend at Pitlochry was once again well attended with the Atholl Centre fully booked. Caroline Aitken and Lesley Kinnear continued their sterling efforts, organising and running the weekend. Esther, Lyndsay and I stayed in the Association caravan over the weekend spending time with everyone, it was good meeting up with the regulars and meeting the new families; the weekend was a huge success. Hopefully Caroline or Lesley will give a report on the weekend later. I would like to thank Caroline and Lesley on behalf of everyone who attended and of course, committee for their hard work organising another very successful weekend.

After the success of last year's days out at Glasgow Science Centre, Heads of Ayr and Almond Valley, committee agreed Caroline and Lesley could organise a further three events this year. The events will be at the Science centre the first of which has taken place and again I hope Caroline or Lesley can say few words on the day out.

The Glasgow branch annual trip "doon the water" to the Isle of Cumbrae took place this year on the 2nd June, the weather was superb although the rest of Scotland had heavy showers, thunder and lightning; we were blessed on the Isle. Our numbers were down again, I think a combination of weather forecasts and no BBQ on offer took its toll. It has been agreed the BBQ will be reintroduced next year as we have a volunteer to pre-cook the burgers on the Friday prior to the event.

Christmas cards have been delivered to Sandra and will be available to areas soon. As we have less areas to service this year Sandra will be distributing the cards based on previous sales, if you would like cards to sell in your area please let Sandra or myself know and we can get this organised for you. Once again this year's designs were chosen by Elaine Wardrop assisted by myself, we had a big issue with CCA not having many of the designs we first chose due to them not informing us the catalogue was available early and other charities placing their order before us. We did manage to get a good range of designs which we are hopeful everyone likes and sales are not affected. Huge thanks to Elaine for placing the order and for putting up with the hassle of dealing with CCA. I would also thank Sandra and Brian Parkins for taking delivery, checking quantities and sorting out the allocations as they have done for the past twenty years and more. Thanks also to Scott Wardrop for supplying the transport to bring cards down to the central belt.

The charity website although under used continues to give out good information to the public and members who use it, although facebook seems to be the media most of our members use these days. The website however contains information in the lead up to the family weekend and has a link to a booking form. It also has information leading up to events such as today's AGM so members can keep up to speed with events through the web pages. The association caravan availability is shown on the website a very useful tool for members who want to make use of the caravan. Sandra Parkins has looked after the bookings since we first put a caravan on Faskally Caravan Park 25 years ago, Sandra and Brian have managed everything to do with running the caravan on behalf of all our members in that time.

I am sure I speak for us all in thanking Sandra, Brian and their family for all their hard work over these 25 years. The Parkins family will now take a well deserved step back and leave the running of the caravan to others.

Bookings for the Caravan are now being taken by Pauline Lorimar, maintenance is looked after by Frank DelPippo and we now have a cleaner going in after families move out to ensure all is well. Brian had highlighted the ramp and decking was deteriorating, this being a safety issue it was agreed to replace it all. A company are on site undertaking this work as we meet.

I would like to thank my fellow trustee's and management committee 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 representatives who come along to the Scottish committee meetings; without whom the charity could not function.

Special thanks to Willie Gunn for his work as treasurer including the financial reports made available at every meeting and preparing the end year accounts.

Thanks to Grant for recording the minutes of our meetings and Lyndsay when Grant has been unavailable. Thanks also to Grant for organising today's venue

and last but not least thanks to each and every-one of you for coming to today's AGM.

John Fegan

Chair

June 2018