



ECHG Report 2012 - 2014

The Vision:

A world where everyone born with a heart condition receives excellent medical care, where adults born with these conditions (known as GUCHs or ACHDs) lead healthy happy lives and reach their full potential supported by effective patient led organisations.

In 2012 the following were elected to the ECHG

- Isabel
- Torben
- Anneke
- Gill
- Monique
- Paul

And as helpers

- Joris
- Graham



Meetings? Oh we did meetings

From 2012 to 2014 we...

- Met c70 times online
- Sent and read c800 emails
- Met physically once
- Spoke at an International Cardiology Conference
- Tackled the main project given to us
 - Whether we should set up a formal European organisation

Approach

Main thrust - Do we need a formal European GUCH organisation?

- Cost Benefit Analysis
 - Benefit = what do organisations want
 - Cost = € (real € or time).
 - If benefits > costs – then do it
 - If benefits < costs – then do something else to get the same benefits
- Survey

Other work

- Keep the network of organisations active
- Newsletter
- Facebook page
- Principal Contacts list
- Survey
- Build structures not for this two year term, but for the future

Built ECHG Structures for the future

- Centralised email account – not linked to an individual
- Facebook presence
- Newsletter – dependent on your contribution
- Set up blog based website – not linked to an individual
- Undertook a survey of what your organisations want
 - More on this later
- Proposed joint work to ECHDO

Survey Outcomes

Survey on www.surveymonkey.com

- 9 questions
- 11 responses

Let's have a look on the questions and outcomes

- Are you happy with what the ECHG is doing? 100% yes
- What else can we do?
 - Work more together with ECHDO
 - More information: we set up a blog and facebook page, send out newsletters with information from the organisations
 - Annual meeting

Survey Outcomes – What else to do? (1)

- How can ECHG help your organisation?
 - contact support 5x
 - information 4x
 - share experiences/ projects of organisations 4x
 - support european meetings 3x
 - networking: being part of a larger/ european organisation 1x

Survey Outcomes – What else to do? (2)

- How does ECHG add value to the international GUCH movement?
 - Sharing of experiences/ Information 5x
 - Awareness/ more influence 5x
 - Central European network 4x
 - Help countries to support GUCH patients/ develop organisations 4x
 - Ensure conferences to continue 2x
 - Get financial support from a European level/ link to European politics 2x

Survey Outcomes – Funding and Fees

- Funding – how can your organisation support ECHG?
 - Not financial 4x
 - Don't know 3x
 - Personal assistance 2x We do support 2x (provision of facilities/ travel costs for ECHDO member)
- Membership fees?
 - Yes 4x
 - No 2x

Survey Outcomes – Costs and Benefits

- The most important benefits of the ECHG are only possible with your help:
 - Share information
 - Share experiences
 - Contact support/ networking

We can do it without the need of funding.

- More work would mean more costs: money and personal assistance
 - Own website
 - Annual meeting (costs of our meeting in London: 1.291,33 €)
 - Costs for registration and running an office

•Funding costs money. Only 4 organisations said yes, we can pay membership fees, 2 said definitively no.

•Only 2 organisations said they could send personal assistance.



Survey Outcomes – Specials (1)

Two special things: responses to the question „what do you want from ECHG“

Organise trips to the best 2 or 3 centres in Europe as a fact finding mission to learn what the top service provision is in Europe.

- Who pays? Who takes part on these trips?
- Who decides which the best centres in Europe are?
- What consequences result?
- Suggest an interim step: Ask organisations what standards their services are based on, and whether the services are held to account – this is written and ready for the next ECHG to take forward

Survey Outcomes – Specials (2)

Providing a directory of the specialist GUCH centres in Europe for those who travel in Europe.

- Who decides which hospital appears in this guide?
- E.g These data change constantly. New centres appear/disappear. Who does the work of constantly updating the information?
- Suggest all organisations offer help to travelling GUCHs – just answering the question on where would you go?

Way forward:

Recommendations for the next ECHG Working Group

- Meet in person twice
- We found it useful to keep focused, and re-invigorate people
- Keep talking
- Have a timetable to work to

Way forward: For the European Congenital Heart Community

- Survey does NOT suggest a formal organisation will meet the desires of the organisations
- Input to newsletters & responses to emails can be erratic
- Suggest a more formal alliance, short of a formal organisation

Questions and further work



Election of ECHG

- Torben (Germany)
- Gill (Scotland)
- Krista (Finland)
- Katerina (Cyprus)
- Anna (Greece)

- Helpers
 - Joris (Belgium)

Conference 2016 & 2018

- ✓ 2016 – Scotland
- ✓ 2018 – Finland
- ✓ 2020 – Cyprus
- ✓ 2022 – Belgium