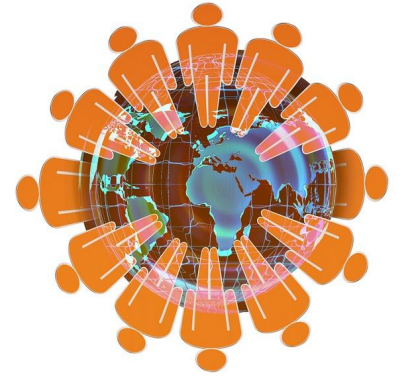




FOXG1 Point of Contact (POC) Project

Purpose of the **P**oint of **C**ontact **P**roject

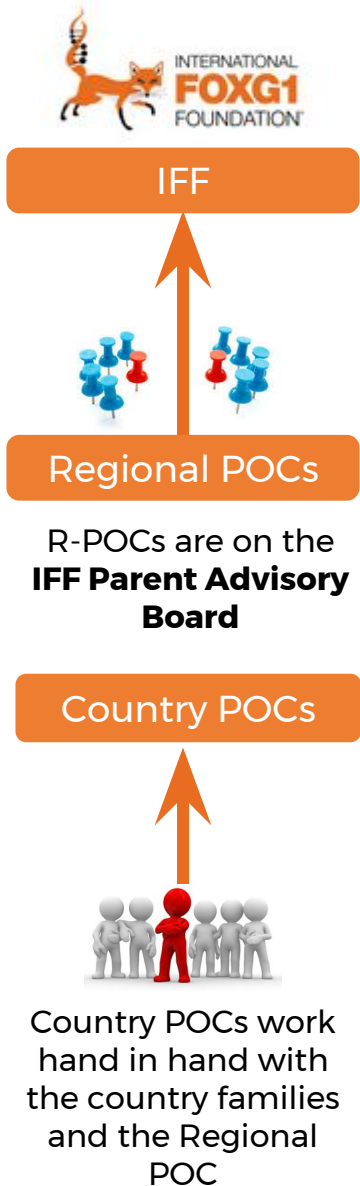


- One of the International FOXC1 Foundation's goals is to promote global communication and input
- This conduit will give the IFF a way to hear from our families globally on your needs and questions
- It will allow the IFF to be as transparent as possible by providing all families information translated into their language
- Families will be able to provide feedback on information received, and also notify IFF of research & fundraising opportunities available in their countries/regions



Structure

FOXG1 World-Wide Structure



Country Organisations

Country Entities are **entirely independent** from the IFF but **work together** on Research, Fundraising and contact databases

1. There is an International FOXG1 Foundation based in the USA (IFF)
2. There are *independent* country FOXG1 entities (associations, foundations, organisations).
3. Each Region has a Regional POC (R-POC) who is on the IFF Parent Advisory Board (PAB).
4. Each country entity has a POC who works hand in hand with the R-POC.
5. For Countries without official entities, there will be a parent POC representing families.
6. The IFF collects patient data centrally.
7. Research can be funded jointly, by each entity (example: a Researcher in Italy is mandated by the IFF for a \$100'000 project. The IFF may participate with \$50'000 and other entities with other amounts to reach \$100'000).
8. The IFF website has entry web pages in all key FOXG1 country languages offering baseline information, links to other country entities and listing POCs and the languages they speak.

FOXG1 Key Roles of the Organisations & POCs



FOXG1.de



Country Organisations

Regional POCs

POCs

- Spread awareness locally around FOXG1
 - Be the key contacts for the local families
 - Be the key liaison between the IFF and local families
 - Share IFF information in country language with families
 - Fundraise for local or global projects
 - Gather family contact information
 - Engage with local Press / Media on FOXG1
 - Validate / Feedback on global Research Roadmap and projects as well as Funding coordination
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IFF

- Spread awareness in the USA and globally around FOXG1
 - Be the key contact for US-based families and for families where there is no country organisation or no POC
 - Liaise with country organisations and POCs
 - Fundraise in the USA and globally for US-based projects and for global projects
 - Gather family contact information in the USA and for countries where there is no organisation or POC
 - Centralise all FOXG1 family contact information world-wide
 - Be the POC for USA and Global Press / Media on FOXG1
 - Lead the Research Roadmap & projects
 - Lead the Fundraising coordination and strategy
 - Provide multilingual web platform with links to country organisations and POCs and their websites / social media groups
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Regional POC Job Description

- There are three Regions: The Americas (AMR), AP (Asia & Pacific), and EMEA (Europe, Middle East, & Africa). Each Regional POC sits on the PAB.

The Regional POC (R-POC):

- Serves as liaison/coordinator between the International FOXG1 Foundation, FOXG1 organisations /foundations/associations and the POCs in their Region's countries
- Ensures all FOXG1 families have the same level of information through their POCs, sharing key IFF documents with the POCs and getting them translated when applicable (must speak English)
- Builds the IFF website content for key languages
- Supports the centralisation of family contact information into the IFF database, while always respecting parents & patients' privacy
- Gathers feedback from the POCs and is their spokesperson for the IFF, especially on topics of global interest such as Research and Fundraising
- Ensures Fundraising efforts are not duplicated by sharing them with the IFF
- Organises events in their region (ex: FOXG1 family gatherings)
- *The Regional POC will have a backup & delegates tasks above when deemed necessary*



Country POC Job Description

- There are POCs in every country, independently to any local FOXG1 entity (foundation, association, organisation). Each Country POC represents the country's families and works hand in hand with their Regional POC.

The Country POC:

- Serves as liaison/coordinator between their Regional POC (R-POC) and the country families
- Ensures all FOXG1 families in their country have the same level of information, sharing key IFF documents with the families in their language
- Maintains the list of contacts for their country, centralise the family contact information into the IFF database, while always respecting parents & patients' privacy
- Is the FOXG1 country point of contact for Press, Media, Researchers, Doctors, etc
- Gathers feedback from the families and is their spokesperson to the R-POC, especially on topics of global interest such as Research and Fundraising
- Ensures Fundraising efforts are not duplicated by sharing them with the R-POC
- Organises events in their country (ex: FOXG1 family gatherings)
- *The Country POC will have a backup & delegates tasks above when deemed necessary*



Interested in Applying?

Please contact the Project Managers:

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