

Global Coalition of Parents of Children
who are Deaf or Hard of Hearing
(GPODHH)



ANNUAL REVIEW

2023





Our Vision

An inclusive world in which children and people who are deaf or hard of hearing, and their families live meaningful lives on an equitable basis with others.

Our Mission

The Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPODHH) is an international collaboration of parent-led groups and parent leaders dedicated to promoting improved systemic protocols and practices which encourage informed choice and the empowerment of families with a deaf or hard of hearing child throughout the world.

Our values

We embrace:

- The diversity of experiences and knowledge that exists due to geographic, cultural, social and economic situations
- Parents' right to choose what is best for their child and family
- Family support programs that promote parent-to-parent contact and trained adult role models/mentors who are deaf or hard of hearing.
- Parent empowerment to be agents for change
- Social justice for all children who are deaf or hard of hearing and their families – human rights, access, participation, equity



Message from the Co-chairs



Ann Porter

Australia

We are delighted to present our first Annual Review for the Global Coalition of Parents of Deaf and Hard of Hearing Children (GPODHH). We feel it is time to highlight the achievements of this voluntary group of passionate parent leaders from around the world over the past year.

Since its grassroots beginning under the trees on the sideline of the NHS Conference in Italy in 2008, GPODHH has evolved into a resilient organization, making a significant impact on the global stage. The journey of GPODHH has been a testament to the challenges of not just starting but sustaining a movement. Through the inevitable ups and downs, GPODHH has maintained its identity and experienced growth in both membership and impact. This growth has been instrumental in ensuring that the organization remains an important advocate for children and young people who are deaf or hard of hearing (DHH) and their families.

GPODHH has established itself as a close associate of FCEI International and an active member of the World Hearing Forum and Cochlear Implant International Community of Action (CIICA). Regular participation in seminars and discussions and presenting parents' perspectives on international platforms has solidified GPODHH's presence and influence globally. The organization's involvement in these networks has allowed it to contribute to shaping policies and guidelines that affect DHH children and their families worldwide.

Through its international collaborations, GPODHH receives regular requests for consultation on policy documents, research outputs and other collaborative endeavours. For example, GPODHH members are

part of the team producing the revised Best Practice Principles for Family-Centered Early Intervention (in press) and are leading the development of the easy-read version of the Principles. GPODHH members have a broad range of lived experiences, knowledge and perspectives, and their insights provide important and valuable input to these organisations.

However, as the realization of the crucial role that families can play in the development of programs and research agendas grows, the stark reality of sustaining parent groups is ever present in our meetings. Funding is a constant difficulty for every organization. Most continue to operate because of parents' passion for building a better world for their DHH children. Volunteering results in a high attrition rate, and valuable parent knowledge is lost when parents are not compensated for their contribution. Sustaining effective parent organisations requires funding. As GPODHH continues to evolve and grow, there is a pressing need for policymakers, program managers, and researchers to factor in funding for family support and consultation when developing their budgets. It would make a world of difference.

In conclusion, the journey of GPODHH, from its humble beginnings under a tree to its current status as a global advocate for DHH children and families, is a testament to the resilience and determination of parents committed to making a lasting impact on the world stage. The organization's achievements and ongoing efforts underscore the importance of collaborative advocacy and the power of collective voices in creating positive change.

As the co-chairs of GPODHH, we embrace the “Declaration on the Rights of Deaf Children” and the imperative that language be accessible to every deaf child. We challenge governments to recognise the importance of language – both signed and spoken – and the rights of deaf children to protection from language deprivation so they can lead productive lives with dignity and self-worth.



Snigdha Sarkar

India

Highlights of 2023



Advocacy

- World Hearing Forum
- FCEI International
- Cochlear Implant International Community of Action (CIICA)
- Coalition for Global Hearing Health



Knowledge

- Co-design in research, policy and project development
- Family-centered early intervention principles
- Child safeguarding
- Childhood hearing screening
- Parent leadership development
- Webinars



Governance

- Three-year strategic plan
- Policy documents
- Position statements
- Bi-monthly meetings
- Knowledge and resource sharing

Highlights



World Hearing Forum

- GPODHH is a member of the World Hearing Forum (WHF) and is represented in 2023 by Snigdha Sarkar (India) and Joyce Sserunjogi Nalugya (Uganda). They attended the WHF Members' Meeting in Geneva, Switzerland in November 2023.
- Snigdha Sarkar joined the World Hearing Forum Steering Committee for 2023-2025, co-chairing the World Hearing Day Work Stream.
- Dr Joyce Nalugya participated in a panel discussion on "Hearing Care: Societal Perceptions" at this meeting.
- GPODHH representatives are leading contributors to Changemakers and World Hearing Day Work Streams.

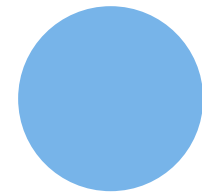
FCEI International

- GPODHH is the official parent organisation of FCEI International - a collaborative, multi-disciplinary, worldwide network of parents, families, professionals and researchers, both DHH and hearing, who are engaged in promoting and improving evidence-informed practice and research in Family Centred Early Intervention (FCEI) for deaf and hard of hearing (DHH) children and their families.
- Leeanne Seaver (USA) represents GPODHH on the FCEI Executive Committee.
- Bianca Birdsey (South Africa) led the GPODHH working group for the revision of the FCEI Principles and is an author for the paper (in press).



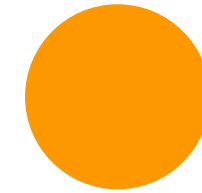
Acknowledgement of support

GPODHH is a voluntary organization with no funding. Member organizations provide their representatives (parent leaders) with the necessary financial support to participate in GPODHH activities. We wish to thank all our supporters including:



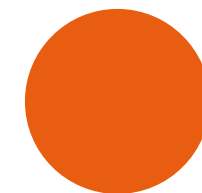
World Health Organization

The World Health Organization has encouraged and supported the GPODHH representatives to attend the World Hearing Forum meetings in Geneva, Switzerland.



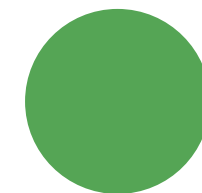
FCEI International

FCEI International has supported GPODHH since the first FCEI Conference in 2012. The organisation provides financial assistance for our bi-ennial meetings held in Bad Ischl, Austria.



Aussie Deaf Kids

Aussie Deaf Kids (Australia) provides financial support for the GPODHH website and our representatives to attend the meetings of the World Hearing Forum in Geneva.



Hands & Voices

Hands & Voices (USA) provides access for our bi-monthly meetings and webinars.



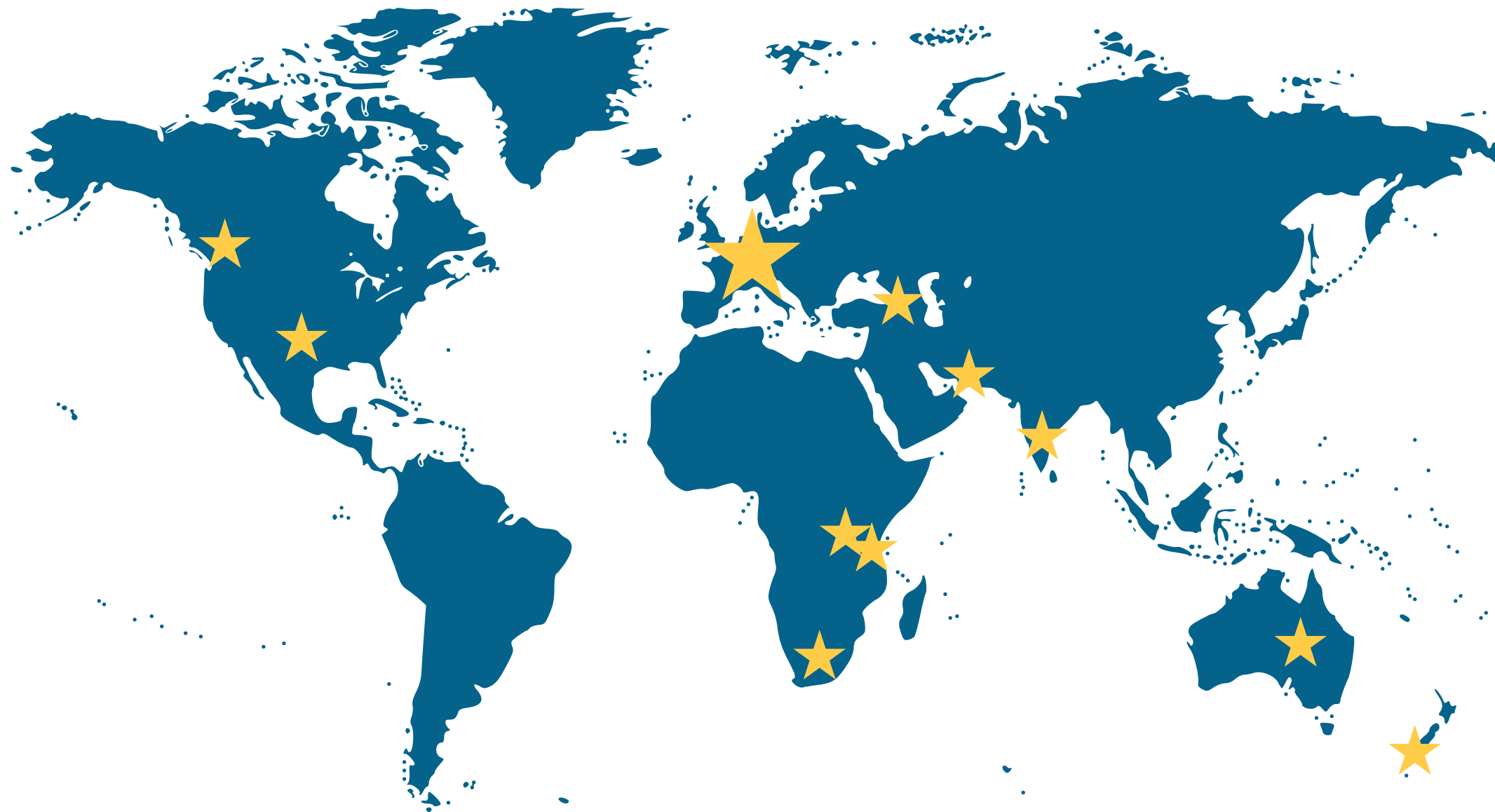
Parent leaders

Our parent leaders are all passionate advocates for children and emerging adults who are deaf or hard of hearing and their families. They volunteer their time and expertise to support the work of GPODHH.

Member organizations

GPODHH has three levels of membership - full member, associate member and individual member.
Member organizations are registered in their country and parent-led.

Australia: Aussie Deaf Kids
Austria: Gemeinschaft Eltern und Freunde Hörgeschädigter
Canada: BC Hands & Voices
Europe: FEPEDA - Fédération Européenne des Parents d'Enfants Déficients Auditifs
Georgia: Aures Foundation
Germany: Elternvereinigung hoergeschaedigter Kinder in Hessen e.V.
India: Anwasha Kolkata
Iran: Parvaneha Association
Ireland: Sharing the Journey
Italy: Dai Genitori ai Genitori



Kenya: Pamoja Parents of the Deaf Children
Lithuania: PAGAVA - Lithuanian Association of Families of Deaf and Hearing-Impaired Children
New Zealand: NZ Federation for Deaf Children Inc
Romania: Asociatia națională a persoanelor cu deficiente de auz din România „Asculta Viata!”
South Africa: Thrive
Switzerland: amplify
Uganda: National Association of Parents of Deaf Children (NAPADEC)
United States: Hands & Voices

Governance

The Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPODHH) is an international collaboration of parent-led groups and parent leaders. The organisation is entirely voluntary and operates under a Charter which outlines the guiding principles of membership and responsibilities of representatives.

GPODHH does not hold direct funds. Member organizations provide their representatives (parent leaders) with the necessary financial support to participate in GPODHH activities. Funding guidelines promote open, transparent and ethical funding principles.

Consensus decision-making is a hallmark of our collaborative practice.

Bi-monthly meetings of member representatives are held online. The co-chairs meet weekly to progress the work of GPODHH.

A biennial meeting is held in Bad Ischl, Austria, prior to the FCEI Conference with the support of FCEI International.



GPODHH – history in brief

2008	<ul style="list-style-type: none"> The Global Coalition of Parents of Deaf and Hard of Hearing Children is established under the trees at NHS 2008 in Lake Como, Italy. Founding parents – Leeanne Seaver and Janet DesGeorges (Hands & Voices, USA); Ann Porter (Aussie Deaf Kids); Roz Keenan (Deaf Children Australia); Jodi Cutler (Affrontiamo Forum, Italy), and Pauline Walker (National Deaf Children’s Society, UK).
2009	<ul style="list-style-type: none"> GPODHH (initially GPOD) undertakes a global online survey of families and their support needs. 600 respondents from 23 countries. www.GPODHH.org is registered as a domain name with the assistance of Hands & Voices. A logo is created and the first website is developed using a free platform.
2010	<ul style="list-style-type: none"> GPODHH publishes its Position Statement and Recommendations for Family Support in the Development of Newborn Hearing Screening Systems (NHS)/Early Hearing Detection and Intervention Systems (EHDI) Worldwide (June 2010). Results of survey presented at NHS 2010 in Como, Italy.
2012	<ul style="list-style-type: none"> 1st International Conference on Family-Centered Early Intervention (FCEI) hosts delegates from around the world in Bad Ischl, Austria. GPODHH invited to organize a pre-conference workshop for parents. GPODHH representatives participate in Consensus meeting following the FCEI Conference and contribute to the development of the principles on family-centered early intervention for children who are deaf or hard of hearing.
2013	<ul style="list-style-type: none"> ‘Best Practices in Family-Centred Early Intervention for Children who are Deaf or Hard of Hearing: An International Consensus Statement’ (Moeller et al, 2013) is published by the Journal of Deaf Studies and Deaf Education. Contribution of GPODHH members recognised in publication. Leeanne Seaver (Hands & Voices, USA) is elected GPODHH Chair.
2014	<ul style="list-style-type: none"> 2nd International Conference on Family-Centered Early Intervention held in Bad Ischl, Austria. GPODHH organizes the pre-conference parent workshop. Communication between GPODHH members mainly through emails.
2015	<ul style="list-style-type: none"> GPODHH commences holding regular meetings on Skype although technology and time zones are barriers to effective real-time communication. A closed Facebook group is created by Jodi Cutler (Italy).
2016	<ul style="list-style-type: none"> Bianca Birdsey (South Africa) chairs the Family Support Committee. Teresa McDonnell (Ireland) chairs GPODHH’s Strategic Planning Committee. GPODHH organizes the pre-conference parent workshop at the 3rd International Conference on Family-Centered Early Intervention. Membership of GPODHH grows as new connections are made at the conference.

2017

- Members of GPODHH participate in FCEI Africa Conference held in Johannesburg, South Africa.

2018

- GPODHH holds the first of its biennial meetings in Bad Ischl, Austria, prior to the 4th FCEI Conference.
- The parent workshop focused on strategies to help families and professionals identify DHH children at risk for or experiencing abuse and neglect.
- GPODHH representatives Bianca Birdsey (South Africa) and Anisa Ibrahimovic (Bosnia-Herzegovina) attend the 3rd Stakeholders’ meeting for the WHO programme on prevention of deafness and hearing loss in July at the WHO Headquarters, Geneva, Switzerland.
- Snigdha Sarkar (India) represents GPODHH at Stakeholder Meeting in December at WHO Headquarters

2019

- GPODHH establishes a WHO Working Group to support its representatives at the WHO meetings.
- Bianca Birdsey (South Africa) and Snigdha Sarkar (India) attend meeting in August at the WHO Headquarters, Geneva, Switzerland.
- GPODHH becomes a member of the World Hearing Forum and representatives Bianca Birdsey (South Africa), Snigdha Sarkar (India), Ann Porter (Australia) and Nicole Schilling (Germany - representing FEPEDA) attend the First Membership Assembly of the World Hearing Forum in Geneva.
- GPODHH representatives, joined by Jodi Cutler (Italy) meet with Dr Shelly Chadha following the meeting to discuss the parent partnerships in the work of the WHF.

2020

- GPODHH’s biennial meeting is done virtually as all in-person meeting and travel is cancelled due to the COVID Pandemic.
- Leeanne Seaver (USA) steps down as GPODHH Chair, and a new team steps up: Snigdha Sarkar (India) and Ann Porter (Australia) who will co-chair the organisation.
- GPODHH becomes a member of the Cochlear Implant International Community of Action (CIICA)

2021

- Resources compiled on Child Safeguarding for families and people working with children who are deaf or hard of hearing - addressing the urgency of increased risk of abuse and neglect for DHH children worldwide.

2022

- A small contingent of members joined the biennial meeting which was held prior to the FCEI Conference in Bad Ischl, Austria.
- First strategic plan was approved to shape the work of GPODHH going forward.



Global Coalition of Parents of Deaf and Hard of Hearing Children



www.gpodhh.org



info@gpodhh.org