



## Solutions Group 2

**S4CCC Guideline Series:**

# INITIATING AND SUSTAINING PARENT & PATIENT SUPPORT GROUPS (PSGS)

Propelling Learning Through Collaborative Research  
May 2023



# CONTEXT

## What do we mean by “Parent and Patient Support Group”?

Parents and individuals empathetically support one another via an organizational structure that also provides support to a local cleft team.

## Why are Parent and Patient Support Groups (PSGs) of interest to LMIC CCC teams?

PSGs are an extra resource that supports parents and patients in a structured, unique way. PSGs can also support cleft advocacy efforts and raise community awareness, drawing from the lived experiences of their members. They can also effectively lobby for better resourcing of cleft care.

## How did we develop these recommendations?

A diverse group of 12 cleft professionals participated in a 3-month research ‘sprint’ that included a global survey that was completed by 190 cleft professionals. A second survey was circulated and received 182 responses from individuals in 39 countries who have accessed cleft care. Analysis of the surveys shaped the recommendations which were presented and discussed at the March 2023 S4CCC Conference.

# RECOMMENDATION

## #1



### Recommendation

Enhance awareness amongst cleft teams about the unique importance of PSGs



### Rationale

- Local cleft teams are usually the main conduit to patients/families.
- Cleft teams are key in the delivery of cleft care.
- Only 1/3rd of survey respondents were aware of a recognized local support group.

Note: PSGs can enhance cleft team outcomes by improving family/patient investment in care plans over time. They can also be a great resource for the cleft care team in raising awareness and ultimately broadening the provision of care.



*98% of healthcare professional respondents believe that support groups can improve the lives of children with cleft.*





# RECOMMENDATION

## #2



### Recommendation

Create awareness amongst families affected by cleft of the ways in which PSGs can improve care.



### Rationale

- Patients and their families are often unaware of their unique and potentially important role in supporting local cleft teams.
- Peer connections provide emotional and practical support in navigating cleft care.

Note: Respondents highlighted the advantages of PSGs, especially in orienting new mothers, in cleft nutritional support, and in the sharing of personal journeys.



*It helps to understand more about clefts and assisting my child to have self-confidence.*



# RECOMMENDATION

## #3



### Recommendation

Provide a step-by-step guide on how to initiate a PSG.



### Rationale

PSGs are often driven by passionate parent volunteers. They can be challenging to both get off the ground and sustain. Informal, social media-rooted groups are easier to start, but may lack the accountability and formal structure of an officially recognized entity.

Note: Identifying a coordinator/champion to drive the process forward is a good practice.



*More than three quarters of those connected with a support group said their group received no funding.*



# RECOMMENDATION

## #4



### Recommendation

Cleft teams and PSGs can work together to fill gaps in the provision of care.



### Rationale

Established PSGs can provide embryonic groups with valuable insights on group sustainability. The most effective PSGs have clear goals and action plans which are agreed upon with the local cleft team.

PSGs can have a role in identifying service gaps that parents and patients experience. Working closely with the cleft team, PSG volunteers may also contribute to closing these gaps.

Note: In some LMIC contexts, challenges with feeding and proper nutrition are areas where a PSG can help ensure information reaches the families who need it most.



*We want to improve our support strategies to be able to have better impact in our community.*





# RECOMMENDATION

## #5



### **Recommendation**

Sustain peer support via online resources and communication hubs.



### **Rationale**

Access to an ongoing online, multilingual 'PSG 101' resource would be a benefit in many LMICs. The ability to share information and to download toolkits would be a welcome asset.



*100% of current patient group respondents are interested to connect with other cleft support groups.*





# NEXT STEPS

The recommendations are aimed at improving awareness about the effectiveness of Parent and Patient Support Groups (PSGs) for families affected by cleft from a wide variety of contexts. Whether you have already organized a support group with the involvement of a cleft care team, or your group of volunteers is seeking to start a group, we hope that these recommendations will spark sustainable progress!

In the future, we are enthusiastic about piloting initiatives to grow PSGs across LMIC contexts. We also welcome further research into the impact of PSGs upon local cleft care teams' patient outcomes.

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# Additional Resources

*Click to access the following*

[Solutions Group 2 Roundtable Recording](#)

[Key Components of a Thriving PSG](#)

[Patient-Centred Care](#)

[Parent Contact Handbook](#)

[clapa.com](http://clapa.com)

[cleffriends.co.za](http://cleffriends.co.za)

[smilefoundationsa.org](http://smilefoundationsa.org)

[clapam.org.my](http://clapam.org.my)

