

**Chromosome 22 Central  
Engagement Survey Report  
2021**



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## Executive Summary

Chromosome 22 Central, Inc (C22C) is a not-for-profit advocacy network for families affected by disorders of the 22<sup>nd</sup> chromosome. The network was initially established in 1996 to support families affected by Emanuel Syndrome but grew to include all families who had members with any chromosome 22 disorder. Now in its 25<sup>th</sup> year of operation, the organization supports nearly 4000 members globally via a strong digital presence. For the first time in its history, C22C reached out to its members with an engagement survey to solicit their feedback on the network's activities and gain insight into their needs and perceptions as families affected by rare chromosomal disorders. Responses to the survey are intended to help inform C22C's five-year plan as well as some immediate programmatic decisions.

## Key Findings

1. Nearly 84% of the respondents were mothers of children with rare chromosomal disorders, with fathers' participation being limited to 7.5%, demonstrating the predominant involvement of mothers in C22C. More than half of the respondents were from the United States of America (USA).
2. Close to one-third of all respondents' access C22C social media daily. The most frequently given reasons to join the C22C Facebook group were to connect with people in similar circumstances (88.2%), find emotional and moral support (66.7%), and access updated information and research (64.5%).
3. Majority of respondents said they were interested in expert sessions. The topics that are of most interest include research and updated evidence (66.7%), chromosome 22 disorders (65.6%) and education and therapy (57%). A larger proportion of respondents would prefer online sessions, most likely attributable to the current COVID context.
4. While approximately 42% of respondents said they were not willing to volunteer, nearly an equal proportion said they wanted 'more information', and more than 18% said they would volunteer. Promisingly, 54 respondents (58%) chose an option stipulating what they could contribute to C22C as volunteers. The most popular tasks were being a regional C22C coordinator, helping with social media, and helping organize events.
5. Respondents provided valuable qualitative feedback as well which highlighted what they already appreciated about the C22C group and how it had impacted their lives. Moreover, they were also asked to suggest how C22C could better serve the families in future. While most echoed the sentiment, "*Keep up the great work that has been happening over the years.*", there were also some suggestions to "*Continue telling our stories and advocate for increased awareness*" and "*Break down into several age groups so families feel supported as their children grow up and become adults and have different needs to when they were babies.*"

# Survey Report

## Background & Objectives

Chromosome 22 Central, Inc (C22C) is a not-for-profit advocacy network for families affected by disorders of the 22<sup>nd</sup> chromosome. Operational since 1996, the network was initially established to support families affected by Emanuel Syndrome but grew to include all families who had members with any chromosome 22 disorder. The organization supports nearly 4000 members globally via a strong digital presence. The C22C website is focused on hosting information on disorders, health services, research opportunities, literature, and event updates. Additionally, the organization is active on social media including Facebook, Instagram, and Twitter; where members can connect, share information, ask questions, and seek support.

C22C is keen to evolve and enhance its future activities. In order to plan better for this goal, the organization conducted the C22C Member Engagement Survey with the following objectives:

- solicit member views and feedback on existing platforms and activities
- improve understanding of the needs and expectations of member families
- enhance engagement of members in C22C activities
- explore opportunities for enhancing the C22C network

## Methodology

Guided by the survey objectives and consultations with stakeholders, the C22C team developed a survey questionnaire in Google Forms. The survey was composed of 29 questions divided into 4 sections: member demographics, website and social media presence, key needs of the families and a concluding part on feedback and suggestions. The questions were both quantitative and qualitative in nature. The data was downloaded in the form of an Excel sheet and quantitative data was also analyzed in Excel.

The survey link was shared via the organization's social media channels; primarily Facebook. The link was available for 04 weeks, from January 24<sup>th</sup>, 2021 to February 20<sup>th</sup>, 2021 and received 93 responses.

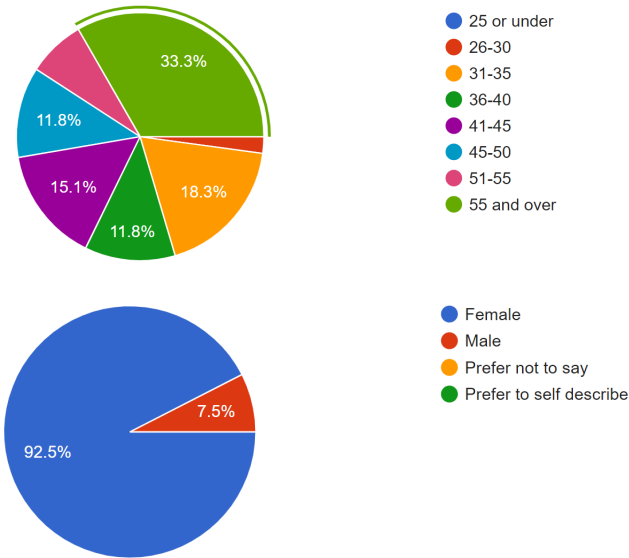
## Survey Results

### **Respondents Profile**

92.5% of the respondents were females, reflective of the predominant engagement of mothers in the C22C group. The 7.5% males (n=7) were all fathers with a child affected by a chromosome 22 disorder (Figure 1).

Vast majority, 89.2% (n=83), of the respondents were parents to a child with a chromosome 22 disorder, while one respondent had a sibling with a chromosome 22 disorder, and another had a relative with the same. Three of the respondents had children with rare chromosomal disorders other than those of chromosome 22. Given the high ratio of parents, it was not surprising that all respondents were more than 25 years of age with over 40% (n=38) more than 50 years of age (Figure 1).

More than three-fourths (75.3%) of the respondents were members of the C22C group for more than three years, while it was encouraging to see six new members (< 6 months) also take the survey.



**Figure 1: Age and Gender Distribution of Respondents**

More than half (55.4%) of the respondents were from the United States of America (USA), followed by 20.6% from the United Kingdom (UK) and 16.3% from Canada. C22C’s global reach was also reflected with responses coming in from Cyprus, Ukraine, Italy, Netherlands, Norway, South Africa, and Australia (Table 1).

**Table 1: Country-Wise Distribution of the Respondents**

Country	Number of Respondents
United States of America	51
United Kingdom	19
Canada	15
Cyprus	1
Ukraine	1
Italy	1
Netherlands	1
Norway	1
South Africa	1
Australia	1

### Family Engagement

Nearly half (48.2%) of the respondents said that none of their other family members would like to be involved with C22C. However, 31.3 % said that their spouses, 19.3% said their children, and 15.7% said that their extended relatives (15.7%) would like to be engaged with C22C.

The survey also captured various suggestions regarding family engagement from some of the respondents. Most respondents felt that engagement via *social media*, especially Facebook, was an effective way to engage other family members, though one individual opined that C22C needed a ‘better social media platform’ to enhance the same. A couple of respondents mentioned that connection through social media is especially key to enhancing the interest of young adults, with an added opinion that youngsters tend to prefer Snapchat and TikTok - with ‘more video, and less text’ - as compared to Facebook. One respondent also suggested having subgroups on social media for other family members such as siblings. Another

member suggested to having a page or resources which would help family members who live separately but want to be involved; such as a gift ideas page.

Though social media was the most mentioned platform to drive family involvement, one respondent also proposed newsletters to keep families engaged.

Having more *gatherings* was another idea given to increase family members' engagement. There was a suggestion to engage young adults online complemented by annual gathering in their respective areas. Sharing more *information* on the disorders including latest research and advocacy approaches was also a strategy that respondents felt would interest family members.

Some interesting and contrarian takes on family engagement must be mentioned. A mother said that she would actually prefer *not* having her extended family involved with C22C Facebook accounts as she views these groups as her own private space where she can be open. A member from UK commented that her family was very private so hence would not be interested in engaging with the group.

### Digital Engagement

**Facebook:** The most frequently given reasons for joining the C22C Facebook groups were the opportunity to connect with people in similar circumstances (88.2%) and finding support (66.7%). In addition, locating updated information and research on C22 disorders and asking questions were also motivators to join the Facebook groups.

32.3 % of the respondents accessed the C22C social media daily, while 21.5% and 6.5% logged in weekly and monthly respectively. A sizable group accessed it on an as-needed basis (32.3%). Very few respondents (7.5%) said that they 'rarely ever' accessed C22C social media.

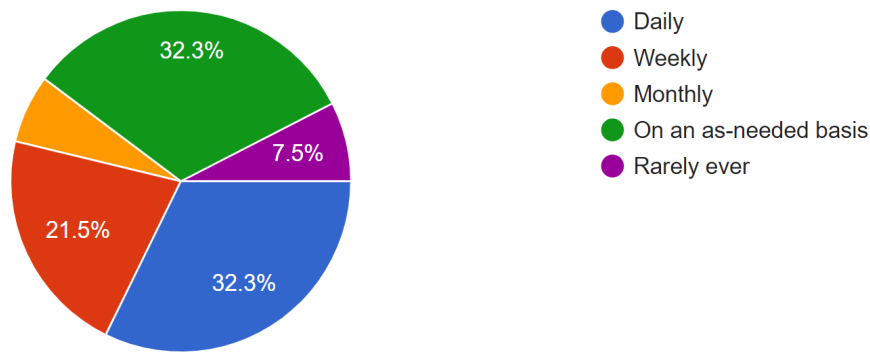


Figure 2: Frequency of Accessing C22C Social Media

**Website:** The most frequent reason to visit the website was accessing information on C22C disorders (63.3%), followed by finding current research (60.8%) and accessing links to other resources (48.1%). 21.5% stated finding information on upcoming events as the reason for visiting the website.

Most respondents (60.2%) accessed the website on an as-needed basis, while 11.8% and 5.4% visited it weekly and daily respectively. Ten (10.8%) respondents claimed that they had never visited the website while four (4.3%) respondents were unaware there was a C22C website.

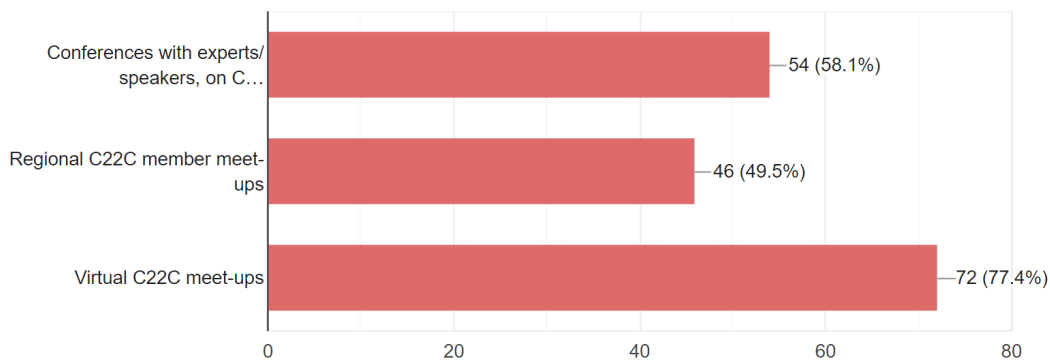
### C22C Events and Sessions

The survey also explored member's interest in expert sessions on C22C disorders and other in-person and virtual events.

Though more than half (53.8%) of the respondents showed an interest in expert sessions, a significant percentage (38.7%) of them were unsure, while 7.5% (n=7) were not interested at all. The 7 “non interested” respondents were from the 55 and over age group, who, understandably, would have substantial experience and knowledge.

The most preferred format for expert sessions, chosen by 34.9% of the respondents, was Facebook live sessions with Q&A in comments. A significant ratio of respondents (26.7%) voted for pre-recorded sessions with questions shared in advance, while 18.6% preferred only a written Q&A session. In addition, there were also some votes for Instagram live sessions, Zoom calls, and in-person sessions; with seven respondents saying they would be fine with any format!

When asked what events they would be willing to attend, majority of the respondents’ votes (77.4%) were for virtual C22C meet-ups, with substantial votes as well for conferences (58.1%) and regional C22C member meet-ups (49.5%) (Figure 3). It is noteworthy however, that 30% of the respondents only voted for virtual C22C meet-ups.



**Figure 3: Member Interest in Events**

Although nearly 70% of the respondents voted for conferences and regional meet-ups, nearly half (49.5%) were unsure about attending in-person and only 37.6% said they would be willing to attend events in-person. A total of 12 respondents said they would not be willing to come to in-person sessions. The high proportion of respondents who are unsure or not willing to attend events in-person is most likely also attributable to the current COVID-19 pandemic.

### **Volunteering**

Majority of the respondents (41.9%) said they were not interested in volunteering. However, 17 respondents said they were willing to volunteer while 37 respondents said they wanted more information. It was promising that 54 respondents chose an option stipulating what they could contribute to C22C as volunteers. The most popular tasks were being a regional C22C coordinator, helping with social media, and assisting to organize events. Additionally, some respondents also stated their specific skills that could help C22C. Appendix A summarizes information on volunteers who gave their contact details for engagement.

### **Resources and Information**

The topics in which members were most interested to find more information are “research and updated evidence” and “chromosome 22 disorders.” Table 2 given below summarizes all topics with the votes they received.

**Table 2: Respondent Votes on Topics of Interest**

	<b>Topics</b>	<b>Votes</b>
1.	Research and updated evidence	62

2.	Chromosome 22 disorders	61
3.	Education and therapy	53
4.	Caring for your child	52
5.	Family advocacy	39
6.	Diagnosis and testing	31
7.	Information on specialist clinics in USA	25
8.	Information on specialist clinics globally	22
9.	Other chromosomal disorders	6
10.	Other topics: Siblings & future, Adult services, SSDI	1 each

More than three-fourths of the respondents (76.3%) were content with resources available in English. However, nearly 24% of the respondents expressed that it would be valuable to have resources in languages other than English to cater to members from non-English speaking countries.

The languages that were requested for include Arabic, French, Spanish, Russian, Lithuanian, Ukrainian, Norwegian, Italian, and Dutch. One respondent suggested having an auto translate feature with resources.

### Qualitative Feedback

The survey also proceeded to ask some descriptive questions from the respondents to gain their input and feedback on C22C and its role in their lives.

#### As a caregiver, what support do you seek most from this group?

In answering this question, the word that was used overwhelmingly by respondents was **‘information’**. Majority of the members are looking for information focusing on, *‘what doctors here don’t know’*, *‘practical everyday hacks’*, *‘feeding and therapy’*, *‘medical issues’*, and *‘outcomes of children’*.

Some responses regarding information are shown in the text box.

*“(Information on) development stages, what to expect for people with E when they grow up, what to be aware of and common problems.”*

*“To learn more information that will benefit my child, I gain experience with which I may help those who need information in the future.”*

*“Medical troubleshooting with parents.”*

Finding **emotional support** and a sense of community was another leading factor. Being part of a group makes them feel they have *‘friends who understand’*. A respondent declared that it was for *‘just moral support, understanding, and sharing’* while another felt it was what she turned to *‘when feeling burnt out’*.

It is also notable that many parents want to be a part of the group to be aware of and discuss issues of **growing up** and independent living.

#### What are the things you already appreciate about the C22C group?

The friend, family, and community vibe of the C22C group was appreciated by the majority of the respondents. Finding people who *‘are so willing to support one another’*, *‘form real connections’* and *‘get it!’*, was a common theme among the comments given. Some termed the group as their *‘second family’*



while several mentioned the ‘*non-judgemental*’ dynamic of the group that makes them feel open and supported.

The inclusiveness of the group was also appreciated, given it does not focus on one chromosome 22 disorder solely. A member commented, ‘*I appreciate that all 22-related disorders are included and serve everyone.*’ The ‘*international*’ nature and ‘*global diversity*’ of the group was another factor admired by many respondents.

*“The family dynamic and quick responses to questions asked. The super positive attitudes and kind nature of everyone. Everyone shares their knowledge and experiences so easily.”*

*“It’s a wonderful tool for all the young families around the world to be able support each other and share common experiences. Forty years ago, it was such a different story – today’s great technology can help and support each and every one.”*

### **Do you have any suggestions on how we can better serve families in the future?**

While most respondents (52%) expressed that C22C should continue doing its work as it is and did not have any specific suggestions for improvement, many did provide feedback and suggestions.

Nearly one-third of the suggestions were centered around increasing the opportunities for group members to **connect** and engage. Ideas included ‘*more gatherings*’, ‘*local meet-ups, post-pandemic*’, ‘*zoom calls*’, and ‘*virtual hangouts*’. More specifically members suggested ‘*organized group zoom activities for engagement and connection*’ or even ‘*a buddy system or pen-friend option*’. Clearly, a greater interaction with fellow groups members is a priority for many.

There were also recommendations to hold ‘*group discussions*’, ‘*topic-based meet-ups and learning sessions*’ and ‘*educational webinars*’ to enhance **information-sharing** and to remain updated. A few members were also in favour of having monthly newsletters to ‘*share information, celebrations, success stories, products that help, and (details on) fundraisers.*’ Location-based assistance was also suggested by maintaining a list of children ‘*by state*’ (for the United States) and guiding newly diagnosed families to services offered in their state.

Several of the suggestions were focused on C22C’s **digital presence**, with members proposing a ‘*more modern and user friendly*’ website with updated links and information. An online library was proposed with information organized topic-wise and age-group wise. Members felt that as their children transitioned into adulthood, they faced new challenges and required age-specific support. Moreover, resources for ‘*self-care and mental health wellness for caregivers*’ were also suggested to be posted on the website. Considering the importance of advocacy, it was also recommended to house ‘*updated marketing material with more positive success stories*’ on the website to increase awareness.

### **Conclusion & Recommendations:**

C22C is keen to use members’ views and feedback to enhance the network’s presence, improve activities and guide the planning process. The questions were selected carefully and tied very precisely to the uses that would be made of the answers.

Based on members’ responses, it is proposed to prioritize the following.

1. **C22C Regional Coordinators:** Identifying volunteer regional coordinators is of prime importance. This is presented as the first recommendation as it ties in closely with the suggestions that follow.
  - Within the US and Canada, these coordinators could be identified at the state or provincial level, respectively. However, if there are a large number of members in a single state or province, it may be difficult for one coordinator to manage, and two regional coordinators per state or province, would be more practical in that case.
  - For C22C's international members, it is proposed to identify country-level coordinators who can arrange meet-ups, advocate for chromosomal disorders and enhance engagement in their respective countries.
  - As representatives of C22C, regional coordinators can connect with the central C22C for direction, support and troubleshooting if needed.
  
2. **Volunteerism:** C22C should consider working towards starting a formal volunteer program. Given the enthusiasm of several members, it would be a lost opportunity to not leverage that interest and commitment.
  - As mentioned before, engaging regional coordinators would be a helpful and practical first step.
  - Volunteers can also help organize in-person or virtual meet-ups including drafting emails, sending out information, coordinating, and hosting. Regional coordinators can help supervise volunteers to reduce burden on central C22C.
  - Helping with social media, website maintenance and identifying resources are relatively 'low-risk' tasks which volunteers can take on. As their engagement and commitment grows they can be given more difficult tasks such as guiding and providing support to new member families.
  - The process of engaging volunteers can be decided based on central C22C consultations.
  
3. **Family Engagement:** Based on survey results, some suggestions on family engagement are given below.
  - The representation of fathers in the C22C group is much less than mothers. As indicated by survey results, nearly one-third of mothers would like their spouses to be engaged more with the group. It may be valuable for C22C to encourage fathers to connect via dedicated Facebook groups or through local meet-ups (virtual or in-person).
  - In a similar pattern, sibling engagement can also be enhanced. The challenges siblings face are unique, and connecting with others in similar circumstances can be a great support, especially for adolescents. Creating a space on social media apps, such as Instagram or TikTok, where these young people can connect, access information, and find support, would be of benefit to many.
  - Local or regional C22C gatherings are recommended as those would encourage members to attend with their families and improve engagement and understanding. If in-person gatherings are not possible, it would be also valuable for these groups to connect via virtual means such as Zoom.
  
4. **C22C Events:** The survey has revealed that C22C gatherings are of interest to a majority of the members.
  - Till it is safe to hold in-person events it would be best to hold virtual, online meet-ups. As the group may become too large, holding them in stages or holding local or regional meet-ups would be preferable. Regional coordinators would be expected to organize these meet-ups.
  - In-person meet-ups can be organized, if possible, as per local guidelines and rules.
  - To maintain and enhance engagement of members, it is recommended to hold a central C22C gathering or conference on an annual or biennial basis.

- 5. Expert Sessions:** Gaining relevant information is of prime importance to most members, and thus expert sessions are of great value to them. Experts can include (but are not limited to) physicians, clinical geneticists, genetic counsellors, allied health workers, and complex care specialists. The following recommendations are made considering members' preference, convenience of access and the current COVID-context.
- Holding virtual expert sessions via Facebook live, Instagram live or Zoom with questions posted in comments and a moderator guiding the session. Alternatively, questions can be shared with experts in advance. These sessions would have to be announced and publicized in advance to ensure maximum participation.
  - A written question and answer 'session', where questions can be posted on Facebook or on the website and various experts engaged to answer the questions and post them.
  - It is proposed to also engage 'C22C parents' as experts to share their experiences and suggestions. Parents can be part of individual or panel sessions.
  - In-person expert sessions should be prioritized when possible. These can be stand-alone sessions or be included in C22C gatherings or conferences.
- 6. C22C Website Update:** Updating the C22C website should be a priority. Some more specific recommendations regarding the website are given.
- Redesign the website to make it modern and user-friendly.
  - Resources on the website should be organized topic-wise, and preferably also age-wise. Information arranged as per age continuum (newly diagnosed infants, toddlers, school-age children, adolescents, and adult transition) would make it easy to access for caregivers.
  - Links to latest research and evidence should be updated regularly and arranged topic-wise.
  - A biographical section on the website is proposed, where stories of children and families can be posted, including pictures, details of therapy and care, and helpful tips for other families. Caregivers can submit these to C22C who can review and post on the website.
  - Event section can be regularly updated to capture any in-person or virtual events. A 'C22C calendar' would be a good addition to feature advocacy days and events globally.
  - The website should be highlighted more on social media including on Facebook and Instagram, to ensure all members are aware of what is available there.



## Appendices

### Appendix A. Responses to the Qualitative Questions of the Survey

As a caregiver, what support do you seek most from this group?
Information drs here don't know
practical, everyday hacks and advice
sense of community and finding information
To learn more information that will benefit my child, I gain experience with which I may help those who need information in the future
Issues faced when child becomes an adult - living independently/jobs
Advice for therapists (physio, OT, speech)
Support
We are all in it together.
Emotional support
Information
Information, suggestions, encouragement
Friends who understand. Ask questions
After the death of my son I'm here to support others and Stephanie and Murney
Emotional support
Medical information and most importantly support
Only to be kept up with all latest news
Mental health
Just information on outcomes of children
Emotional support, answers to health questions
Not only am I a first time parent, but with a child with a rare disorder. It has been difficult to find other moms who understand what my child has gone/goes through. Just moral support, understanding and sharing.
Emotional support and knowledge
Where to turn when feeling burnt out?
Job and social and recreational resources
experiences and advice from others
Medical questions support.
Sharing information
Medical experiences and emotional support
Contact
Peer support, discussion.
Always good to see parent issues with our family members, and learn from their experiences.
Support and information
Information about medical issues, growth, seeing all the different qualities the kiddos have
Feeding, therapy, medical advice/experiences, emotional support

How to teach and behavior issues
Support & advice
Similar circumstances
Development stages, what to expect for people with ES when they grow up, what to be aware of and common problems.
Un aiuto in tante situazioni diverse: salute, ausili, comportamenti...(Italian to English translation: <i>Help in many different situations: health, aids, behaviors...</i> )
Speech and or Physical Therapy info medical concerns general info.
Info, experience
To be supported emotionally or for opinions, input, or help with a new medical issues.
As a caregiver for 36 1/2 years if an ES Angel I seek now only to contribute where I can, comfort where I can and share a laugh or two when possible.
As a new mother to a child with Emanuel Syndrome I'm really look for information on the syndrome and to see how other child grow and learn with this syndrome
Advice, information and support
Medical troubleshooting with parents
Supported independent living issues
I have feels that im not along
Information, support
How to deal with disabilities
Everyone's experiences on various issues.
ideas for care after parents die
Friends who understand.
Understanding
Just people understand what it is truly like.
Gaining knowledge from others experiences
Help and information
Health issues as my son ages
What i can expect and things to look out for
Emotional
Links with other carers
My daughter is 27 years old this year in June. I need to be with families who have similar aged adults so I can be supported with similar issues.
I love hearing others stories and ideas with their children
Understanding & help with questions
Emotional. We got this!
How others cope with everyday life challenges - what has worked/what hasn't worked/things to question etc.
Advice and medical experiences
Just joined
Information
Mosaic trisomy 22 information
Someone to listen and offer support
Info
Support and information
Info

Please share the things you already appreciate about the C22C group?
Updated on c22c and support
Connecting people
as above
I appreciate that all 22-related disorders are included and serve everyone
I did not understand the content of the question
Research/information/support/kindness
Too new
The sharing of real life situations only others can begin to understand fully
Someone who gets "it" . able to share advice and resources with other. Help others who are new to this group or diagnosis.
Asking questions about our children
International
Regular connection with Emanuel Syndrome families, info on similar medical experiences and suggestions and encouragement with situations that come up
Friends I have made
Long time fan! People are so willing to support one another
The families. We form real connections.
Information and research shared
Support and sharing
Connecting with other parents.
Not feeling alone
It's a wonderful tool for all the young families around the world to be able support each other and share common experiences. Forty years ago it was such a different story ,todays great technology can help and support each and every one.
Family
Community
Everyone always answers questions without any judgment
Sharing information and giving support
Very welcoming!
The guidance and information we received with our daughter's dx
The support and info provided
Availability
openness, moral support
So supportive, encouraging, it's so nice to be apart of th group.
Getting answers
The fact that I'm able to share issues my child or I may have and get feedback and advice from others with kids like mine.
Family resources
Sharing knowledge and views
Meeting others
Information from specialist and experiences of other members
Meeting other families
Companion ship from people I don't know, who become friends and support.
The links to parent support

Everyone's willingness to be open and share their experiences
The family dynamic and quick responses to questions asked. The super positive attitudes and kind nature of everyone. Everyone shares their knowledge and experiences so easily
All the information
I do not use the C22C group but the ES group has been a great resource of information and a safe space to discuss challenges specific to ES
Connection with others
Having others in similar situation at my finger tips for support if needed.
People sharing good and bad news.
Aiuto e amicizia (Italian to English translation: <i>Help and friendship</i> )
A the BEAUTIFUL pictures and smiles of our children and families
Connecting with other parents
Learning how many things equipment etc. have improved
Info experience comraderie
They are my second family who completely understand what I'm going through and I can count on when in need.
This can be summed up in one statement... MY 2ND FAMILY  
How open and supportive everyone is with everyone.
Was my lifeline when my son was diagnosed. Was no other information or groups in this country
Information, research, medical connections research
See below.
The ability to find out more about 22q11.2
N/A
All the familys a very friendly
Information, Support
Families willing to share their children
How we can openly ask questions (Facebook) without fear of being judged.
Global diversity
I actually have forgotten to access it recently
Information about the many symptoms; ideas for dealing with behaviours/illnesses; non judgemental support from other parents is probably the most appreciated.
Everything
I love my internet family. It's the only socializing I do most days.
Inclusivity, non judgement, knowledge of others
Always someone to answer questions
I like how participants can post a question and anyone can respond.
It convinced a surgeon to explore my daughter's gut whilst we were in for aspiration pneumonia, PRS and floppy voicebox.. and they found she had got gut malrotation and fixed it.
All the information
N/a
Learning about Emanuel Syndrome, and sharing info and experiences with other Carers.
Great as a platform for new families who have children with C22C. Lots of Information and support for the early years fir new families.
A sense of community
It was great to meet people in similar situations. I'm more active in the trisomy 22 Facebook group now
Everything
Emotional support. Feeling of not being on this journey alone
I love seeing family updates, especially birthdays, and how others are thriving
Emotional support.

I love the willingness of families sharing their experiences to help others
Ability to communicate with other parents
Access to research
Supportive and willing to answer questions
I appreciate all the information that helped me when I was pregnant with my mt22 baby
Unknown at this time
Research and info and stories
Support, being in contact with others, new information
Research and info and stories

Do you have any suggestions on how we can better serve families in the future?
No
N/a
there doesn't seem to be much activity on the FB page
Continue telling our stories and advocating for increased awareness
Sorry, I have nothing now
I like the idea of Podcasts
None yet.
No
Keep updated
More gatherings
No
Continued engagement, opportunities for connection and sharing of info and resources
More meet ups
Nothing off hand
Not at the moment.
Educational webinars
Inclusion for our children to be heard in schools, friendships. Kayla has done many wonderful things and we have taught her to be an advocate for her needs.
No
More zoom calls, local meet ups post pandemic
Keep up the great work that had been happening over the years .
Not right now
More virtual hang outs
update information available, more research
No
Not yet
A monthly info letter on certain topics ie therapy would be great
IDK
No
no
No
Group discussion



I think your doing great
No
Maybe a Buddy system or pen friend option
Keep up the good work
I don't believe Stephanie could have done any better with this site, truly amazing and helpful when Olivia was born and great support throughout her life today!
Just an idea (and I think from the questions you're already thinking it) but topic based meet ups/ learning sessions. Maybe specific to regions?
No
Keep information and links up to date
Maybe more direct resources online, or a quick way to learn about the kiddos (biography/pics/specialist)
In addition to all the great things provided already maybe some more things for the family/ friends not in the home for them to support and help them help families they love. Like around the holidays gift suggestions. I know that's a little thing but sometimes there are new things out there that even the primary caregivers don't know about.
No
Updated marketing material (more modern and user friendly web) with more positive success stories and language. Monthly newsletters with: information, celebrations, success stories, products that help, advice; fundraisers. Gathering resources to help families new to the diagnosis of state services that are offered in their state or directing them on how to find those resources. Also encouraging self care and mental health wellness for caregivers. If possible any type of assistance for families in need - meal trains for families grieving or spending days/weeks in the hospital, maybe flowers to funeral services.
NA
Continue what your doing
Keep up the good work.
Va bene cosi!
Just keep doing what you are doing.
No
Continue to be available for them. You do a great job there
Organized group zooms activities themed weekly posts for engagement and connection
As we and our children age, it would be good to zoom with others to share their experience with group homes, at home with support or living with other family members.
Figuring ways to reach those who may not have internet access or maybe even a cell phone. Not sure how you would go about this???
No you are all doing a fantastic job
No
No
Answered in survey I think.
I would love for there to be more specialists in the UK
N/A
Im happy with evrything
An access site for parents with newly diagnosed kiddos for articles, links etc. Maybe an online library of sorts with different topics and then information attached. Information on post school life, group home/residential placements ....getting ready to face that now
A list of locations by state of children with the syndrome
None
No
Post on facebook

I found the transition from child to adult services very difficult. I also find the transition from child to adult very difficult to cope with and navigate. My son is clever enough to think he can make good decisions for himself, but really can't most of the time. That is hard.
It is good already
Just be there
N/A
Not sure
Can families submit short videos of their children or their concerns?
Sometimes i find posts announcing information with the date past. It's algorithms in FB not showing me these things first. I wish there was a, maybe Whatsapp group or something, that pinged people with important dates.
No
N/a
Have a dedicated skilled family carer support director. A role I held until retirement.
Break down into several age groups so families feel supported as their children grow up and become adults and have different needs to when they were babies. I feel from experience the age groups could be birth to 5, 6-11, 12-15, 16-19, 20-23, 24-30, 30 - don't know - not sure what support I am going to need
I think you are and have always been doing an amazing job !!
No
No
More opportunities for connections virtually (for now)
I think you are doing a fantastic job already! Thank you
No
Can't think of anything
No
Share as much information as possible how to help our love ones
Would love to know more how to help children with ces particularly in -UK schools. My child does academically well but does struggle with some stuff but we receive no help because academically she is great!
I found this group by searching for mt22 information, and because of this group I did end up finding the information that helped me with the most difficult time of my life
Newsletters?
More in depth information with specialists and more focus on duplication
Not really
More in depth information with specialists and more focus on duplication

In the end, we would be grateful if you could sum up and share how C22C has impacted your life?
The site and individual on the site have kept me informed and up to date.
The care and advocacy for my child
Knowing other people and families are our there gives a sense of belonging
I was pleased with your good collection. I have very little time. I am very optimistic about that in order to share information that will benefit our dear children. thank you all
I do not use C22C as much as I used to because my child is now living independently, doing well medically and working a job but when I did it was a place I could go to whenever I needed an answer when something came up and I wondered if it was related to 22q11.2. It was a place I could read about

other people experiencing what I was going through and I could breathe again and move forward. It was a place I could refer other families to. It was a lifeline. Thank you. ❤️👍😊
When I first learned of my son's dx, it helped a lot to see the other children.
It has been a reliable source of facts and information that's helped my drs and therapist find a place to start with care, compassion and understanding. I feel like I can go there and throw out a question and some out there that understands my walk will be there to at the very least, listen.
Helped me feel like I am not alone
It helps ypu stay connected
Information
Invaluable for support on this unique journey!
The information the parents have provided helped me to become a better advocate for my daughter. They helped get the right medical care, the right therapies and the right resources for school and community. I would have been lost without them.
You guys helped me get to the person I am now! Eternally grateful
I'm happy to know others who understand me and this life. It can be very lonely being a special needs parent. The connections are everything, being able to talk, laugh and or cry with someone has helped tremendously.
Resourceful
When our granddaughter was first diagnosed at around 3 years of age, I had no idea what her diagnosis was so I quickly googled the name and found C22C website, but found that the address of the group or information was located on Kent Street ( where I actually lived when I was 2 years of age) in Timmins. I clearly thought that is was a mistake and did a search several times to see that the same information kept showing up. I jotted down the telephone number and called. When I did speak to the woman at the other end, I heard a voice of excitement, filled with joy that I had reached out, invited me to join the group. I did take her offer and met her, she had zest for sharing, passion, determination, a smile like no other and totally compassionate....her name is Stephanie Rese. We had meetings, lunches, phone calls and support. To this day I appreciate all that she has done for us and others, as we have walked with our granddaughter to better understand her 22q11.22 journey.
Helped me connect with other parents.
A family!
It's been a great source of information and enabled me to support others along the way and when necessary let them know my and my children's journey which personally has been to date, and continues to be , inspiring and humbling in so many ways . 🦋🦋🦋
Great resource, however intimidating when you have a newborn diagnosis.
No
There aren't adequate words. Finding support from people who have been where we are and are where we are has been incredible. The support from other parents has been immeasurable.
Awareness
Seems to be the only group that has any info in the US
If we didnt had this information, we would have struggled even harder, as our daughter's dx is not so known here. We could help guide the doctors.
Helped understand the syndrome. Made some wonderful friend that support each other.
\$ time stress
moral support, a place to seek out advice from other caregivers
It has helped me belong to something bigger than myself and my child's Syndrome, normalizing our new life.
Yes
It has been a huge source of medical and emotional support I won't find elsewhere
Positive

Reassuring that it is a go to resource
An avenue to meet other parents and children
This site has help us throughout Olivia's life ( 15 years old now) with getting answers and what I can expect throughout Olivia's life seeing other children and experiences in the same situation! Would like to see more help from our government for housing with PSW'S for long term care as many parents cannot care for their child forever with their extent of needs ! List of these specific places per province (Canada) and States ( USA) would be helpful to many I'm sure!
Wow! Without the ES Facebook group and the early support thought the book I really just don't know where I'd be. I have wonderful friends from all over the world and we're all connected by C22. It's pretty amazing!
C22C has put me in touch with families in the same boat as us. Advice from those who have dealt with medical issues, surgeries, medications etc. My daughter is 39, there was no information available for me at that time. It's a lonely and sad time when you bring your child home, and try to find your way when medical staff is not familiar with the syndrome. This group is the answer parents are needing at the time they need it the most.
Been a great source of information
It has given me so much more awareness for my daughter
We got our daughter's diagnosis a month after she was born and this group has been just a wealth of information and support from day one. There are so many times that I have had questions and just look it up on the website or asked, or even searched through previous questions in the FB group. For example- when our daughter started having seizures at 6 months old we already knew what to look for and got her started with treatment right away because of the information we had access to (she's been seizure free for 5 months). Great and easy site to navigate and such a wonderful community.
It has helped me understand more about why my daughter does what she does.
Finding the ES group has been such a huge help at a time where we felt very alone and confused. The support the ES group provides is crucial for our family and we love being able to cheer other ES individuals on and celebrate their accomplishments or support families in times of need.
NA
Confirming that I'm not alone on this journey.
Very good to see other with common problems and how other children look like with similar diagnosis.
È stata una grande risorsa per aiutarci nel difficile percorso di vita di nostra figlia. Grazie! (Italian to English translation: <i>She was a great resource to help us on our daughter's difficult life path. Thanks!</i> )
I've met and made some Wonderful friends and learned a ton of helpful info!! 😊
Makes me feel connected
So alone, million questions, no one doctors especially, were encouraging Did not find Steph, another C22 child until Jen and Julie were 22. Now I see how much better therapy and services are even though there are so many things that could be better. Especially School's, the kids are so smart and need to have the support to express themselves and grow!
It's helpful to know we aren't alone
You have provided the needed information and support to help us deal with the consequences of Emanuel Syndrome or other 22 disorders. THANK YOU
C22c did more than make me feel like I was no longer alone but like many became my 2nd family. Words can not Express how much this meant to me. Besides being a wealth of information that was accessible from knowledgeable people to medical papers there were other riches unforeseen that came with connecting with my ES family that became a part of who I am forever. 💜💙 My undying gratitude for that. 💜💙
In the best way possible, gave me my son.
Very supportive and have many friends that I have grown with and feel our kids have grown together too
Would have been so lost, knew what to expect going forward and shared so much info with physicians
Our daughter was born in 1976 and diagnosed with Cat Eye syndrome, a rare chromosome translocation. This was well before information in electronic or print format was available to us and to her medical team. Our youngest daughter actually found C22C online and felt like her sister's needs

were much more closely related to ES than Cat Eye. This information led to a conversation with our geneticist who confirmed her suspicions. The C22C connection has not only been a source of support for our family but also an opportunity to celebrate the successes and share in the difficult times of other children, youth, adults, and families living with ES. As I read the posts on FB, I am continuously struck by how genuinely connected the families are with each other and how information and support readily flow. It feels like home when you don't have to 'explain' your child to others including some of our own family members! ♥
It makes me who I am
N/A
We are along with ES in Ukraine and C22C for me like a book where I'm getting all information about ES
How has it NOT impacted our lives might be easier :). It has impacted us in all ways but it has also made us better parents, and better humans. We have learned not to sweat the small stuff! As hard as it has been there has been so much love and joy that we wouldn't trade for anything. Zach has taught us SO much.
It has turned our lives upside down, dealing with the disabilities and not knowing what to expect everyday ups and downs of his life
It has made our lives extremely better knowing that we are not alone in this journey!
It's given me an outsource to information.
I have not used it much but am interested in re-igniting interest
I would have had no contact with anyone else with the experiences our family have gone through. I still feel out on a limb most of the time because most of the practical stuff is related to North America - I think the Scottish authorities have a lot to catch up on and I'm afraid I don't have the energy to fight the fight any more - although I'm going to have to soon so that my son gets settled, independently before we get too old to look after him. It's exhausting sometimes.
♥
It made me feel like I'm not alone on the planet. There are others like me who have my exact problems. I'm not sure where I'd be without them.
Without C22C, I would know very little about My daughters syndrome. The knowledge gained from C22C has enhanced our entire family's overall wellbeing as we navigate the many challenges. Forever grateful!
Its given me massive insight into my sons condition
Meeting other families who struggled with the same things I was going through with my son, especially when he was very young, was life changing for me.
Well, the support group is invaluable. It's the people in it that make it so. I trust it now, more than the snr health advisors assigned to manage my daughter's care. That's an important role.
It has opened my eyes to understand other kids
N/a
Enabled me to give the best care to Liam.
I was one of the first members when it was first set up but as it has blossomed and gone on social media platforms, it has just lost its impact. I am not an avid social media person , so don't spend time looking at Facebook everyday , so not in touch with everything that happens. I feel it is not relevant to my adult daughter anymore as she is 26 and her needs have changed. I have no where to discuss her ongoing issues.
It gave me a life line back 23 years ago when my daughter was a baby . I was so lost and felt so alone and you changed that for me . It was amazing the 1st time I actually spoke to another parent with a child with R22 . The internet makes things so much easier these days . But back then the feeling of isolation was debilitating and you changed that fit me . I will always be so thankful and grateful ♥
In the beginning in knew no one with Kyles chromosome disorder. It was through you that I connected with may Mayberry and others. I didn't even have a computer at first but went to a friends house to search your site at times. I was so grateful to find you!
Puts my mind at ease. Enjoy the extended family & extra love & support
Sense of community

My sister has Emanuel syndrome and I am a carrier - I found the group most useful when I was trying for a baby. I am grateful for the support other members shared
With a C22 child we have had trying times, but the unconditional love that we receive make life worth living.
We were told we were alone in the beginning. And knowing there were others that experienced what we had or could relate to our experience was just so amazing. I can never express the comfort and calming spirit this gave us.
Brought me information when there was nothing available, this was back in the 80's
Too early to say at this stage
It was there for me when I first had a diagnoses for my husband and we were told we were the only family in -UK with CES. It was from here that I got genuine information and when we went to genetics they gave us the exact same information. I have learnt a lot from this community.
I'm grateful for all the help and hope this group gave me
Interested in way to share my experience which may help new parents
Helped keep me informed
Support network
Helped keep me informed