



ICOMBO
INTERNATIONAL COUNCIL OF
Multiple Birth Organisations



News From Around The World

December 2015

Chairperson Report



Monica Rankin

Hello everyone,

I can't believe that 2015 is almost over. While it may seem that ICOMBO has been very quiet this year, there have been a number of things happening. We have had volunteers working on translating a booklet from Finnish into English. The booklet is about adolescent twins and looks like it will be valuable to our members with teenage multiples. The Finnish Multiple Birth Association have generously made this booklet available to ICOMBO members and found some people who have volunteered their time to translate it into English. The translation is nearly finished. Once completed, there are a few items that need to be completed before it will be available for members. It is a long process, but I am sure it is worth the wait.

The other exciting thing happening in ICOMBO this year is the work on preparing a survey for sole parents of multiples. The survey has been written and is currently being translated into a number of languages. We hope to have it available early in 2016.

Work has commenced on organising the next meeting of ISTS. It will be held in Brisbane Australia on 20 June 2016. It is only for one day. It is intended to be a short meeting, as a way of providing some communication between ISTS members between the major conferences. I will be attending the meeting, representing the ICOMBO members. Any members who wish to attend will be most welcome. At this stage, no details of a program have been released, speakers etc are still being confirmed. The next conference is scheduled for Spain in October 2017. No details have been finalised at this stage.

Regards, Monica

2016 ICOMBO MEMBERSHIP

All members were recently emailed the details of membership renewal for 2016. If you did not receive the information, please contact Monica at membership@icombo.org

In this edition:

<i>Chairperson report</i>	<i>page 1</i>
<i>Member News</i>	<i>page 2–5</i>
<i>ICOMBO Board members</i>	<i>page 6</i>
<i>And The Survey Said</i>	<i>page 7-12</i>

Members Share All

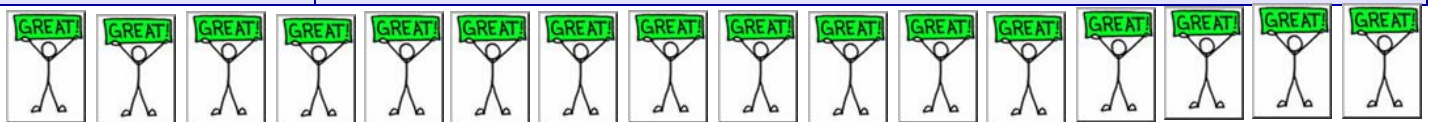
We recently asked our member organisations what has been happening within their organisation during 2015. Below are the responses from the members that responded.

<i>Are there any particular areas that your organisation is working on at the moment?</i>	
Finland	We are planning to apply for finance for a research project, to conduct a study on our family training programme.
Czech Republic	Our work now is concentrated on providing concrete help to families in crisis - we provide baby carers to these families. They are families where the parents are seriously ill, or one of the parents died, or the family are underprivileged. We organized the Public Financial Collection for these families. During 2015 we provided long term help to seven families in crisis.
New Zealand	We have been busy with rebranding the organisation. We are finishing the writing a feeding resource. We are looking at what we do with our Multiple Birth Register - exploring possibility of linking in with Australia. There is preliminary scoping of what we may do for an antenatal resource (future plan).
Norway	We are working on a new website and hope it will be operating in January.
UK (Tamba)	We are running a joint research bursary with the British Maternal Fetal Medicine Society to support applications to undertake the following clinical research: http://www.bmfms.org.uk/TAMBA-Bursaries/c-1-71.htm There is a huge appetite from families to support the research and we would love to partner with other organisations to run an European/international programme too. It has been very positive in increasing support for the charity. We are creating an area of our website for health professionals for online training. We have produced new resources for expectant families. These include factsheets for same sex couples, triplets and higher order multiples (along with videos), one parent families, partners, grandparents. We have produced a pregnancy countdown tool sent by email for all those who register with fortnightly updates. (Translated into Polish, Bengali, Urdu.)
Australia (Multinet)	We are not working on a particular project at the moment.
Australia (Australian Multiple Birth Association)	As a result of a presentation at AMBA's national convention, held in October, AMBA is now working to be more inclusive, initially with special needs families, we're at the beginning of this journey but hope to have more accessible events and more information and resources for clubs to use.
Multiples of America	Multiples of America is focusing on strengthening and growing our membership within our local clubs. If we can assist the local clubs with growth in their membership numbers, the state organizations and of course Multiples of America as the national organization also will grow. We have been working on several ideas within each of our departments to reach out to clubs for assistance.



Member News

<i>Have you had any significant achievements during 2015 that you would like to share with other ICOMBO members?</i>	
Finland	<p>We had a national "Twins carnival" for multiple birth families. We had 1600 people celebrating our 20th anniversary in the amusement park.</p> <p>We published a new booklet for parents of teenage twins and higher order multiples (translation in English is being worked on).</p> <p>We were a member of a committee in Social and Health ministry. It was about problems in our maternal, paternal and parental leaves when it comes to multiple birth families, single parent families, adoption families and rainbow families. We succeeded in having the committee because we co-operated with associations representing single parent families, adoption families and rainbow families in putting the pressure to politicians.</p>
Czech Republic	<p>The first achievement was the Public financial collection which helped us to be able to work with families in need. For example we bought two beds for a family with 5 children, the youngest are twins and they live with only a mother, we paid for surgery for triplet boys with Cerebral palsy, etc</p> <p>The other achievement was the second Twins meeting, where there were more twins and multiples than last year (145 pairs of twins, 5 triplets and one quintuplets). The rarity were the 13 month old twins from New York - they were in Czech to visit grandparents.</p>
New Zealand	<p>We have a new strategic plan including new mission & vision. Change of name to Multiples NZ. We have continued to expand our Facebook presence with more specific interest groups to enable focussed discussion. The latest group is for Rural & Isolated families (i.e. those living on farms, etc).</p>
Australia (Multinet)	<p>We have been spreading information about Multinet through seminars and the national convention and now have quite a few local clubs who have joined Multinet so they can find out some information about school aged multiples, and to help support their parents of school aged multiples. (Multinet is an Australia wide club for multiple birth families, focusing on families where the multiples are school age or older).</p>
Australia (Australian Multiple Birth Association)	<p>In May AMBA announced that Huggies Australia would send every new member, from 1 March 2015, a convenience case of nappies worth \$56. This is an amazing member benefit and is more than the cost of joining a club. Huggies have provided this support to encourage families to join during pregnancy. We're hopeful that this will reduce the number of people who don't connect with support or who connect too late and 'wish they'd know about us before'.</p>
Multiples of America	<p>We finished the design of our new website, and have completed the transition to the new site. Effective December 31, 2015, our old site will be shut down. It is bittersweet because we all loved the nostalgia of the old site, just hated the slowness of it, and the continuous problems we have had over the past few years. We are excited that our new site is fresh, current, and easy for our volunteers to update. We always needed IT support with our old site to update the simplest forms or reports; our new site allows us to upload a file once, and it updates automatically in all areas rather than us trying to remember where all we put it! It may sound silly, but it is little things like this that are such a time saver and a comfort knowing you have everything handled properly.</p>



Member News

Are there any areas of concern (regarding your organisational structure, or issues relevant to multiples) in your organisation that perhaps other organisations could assist with?

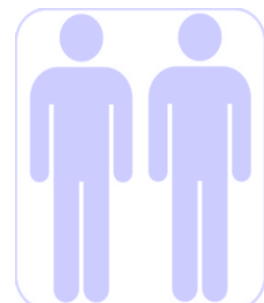
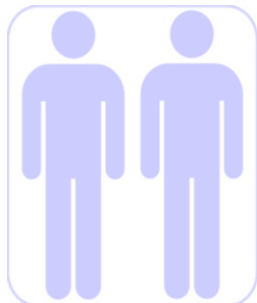
Finland	We have 18 local associations (clubs) as our members nationally. Families are members in those clubs. There has been decline in members from the last years. We wonder how much it is due to social media and especially Facebook, where we have large Facebook groups for multiple parents (groups not organized by official associations) and what kind of co-operation should we have with those groups (we have something but not so much).
Czech Republic	We are not successful with strengthening the position of mothers of twins. The mothers with twins and multiples have no special support neither from the state nor from the municipality. We have identified the problems with caring for triplets and more, but the state (ministry) doesn't want to change the law (the caregivers can't help with baby care, but only to do housekeeping). May be there will be helpful for our argument to know how it works in other countries (the parental allowance, maternity leave, taking into account the number of children at retirement, etc.).
New Zealand	Volunteer recruitment is a major issue for our clubs. Always interested to hear how others manage. I know some manage to keep those with older multiples 'in the fold'. Many of our clubs have very few with older multiples. We are interested in developing a national database (at present individual clubs have their own databases. As a national organisation we have no way to directly contact all our affiliated members. We rely on clubs to pass on information, etc.
Australia (Multinet)	With the push towards cloud technology and various other advancements in technology we are finding there is a reluctance for volunteers to take on committee positions as our membership is mainly of older parents due to the fact their children are at school or beyond. Some other Australian clubs have also stated that some of their members still don't have computers at home. At the national convention, there was discussion about whether to do newsletter in html as opposed to PDF or Doc and quite a few members looked quite out of their depth. So we are concerned that if we set the bar too high it will be difficult to get volunteers with the skill-set and the time to take on positions.
Australia (Australian Multiple Birth Association)	Having up-to-date statistics, eg divorce rate for parents with multiples is a concern as stats of 50% are often quoted but I cannot find the reference for these stats. It'd be great to see an international survey done on this and maybe another organisation is doing one and can add a 'which country are you from' question so we can all share it. Funding is always an issue and we need to work smarter to secure ongoing sponsorship but volunteer time is limited and so many businesses already support other worthy organisations.
Multiples of America	We welcome ideas on membership initiatives and encouraging attendance at events.



Member News

Are there any issues relevant to multiples that your group would like to research at present? Perhaps it could be collaborative with other countries?

Finland	We are planning to apply for financing for research. We want to make study on our family training programme. I think we could collaborate after we have made our study ready.
Czech Republic	I know that every country has different laws and different system of health and social care and children benefits, but I think that there would be interesting to collect the data regarding the benefits for multiples in every ICOMBO country members.
New Zealand	One that has come up recently is hyperemesis gravidarum (morning sickness). We don't have capacity to lead ourselves but would be keen to join in a collaborative project.
Australia (Multinet)	Currently working on issues within our organisation trying to get our website to a better format, converting to internet banking and offering PayPal to pay membership is taking up much of our time and efforts. But if there are any projects you have I would be happy to seek interest from our members/subscribers.
Australia (Australian Multiple Birth Association)	<p>The work Tamba does impresses me and I wonder how we can help them with their fundraising for research, eg TTTS and preventing prematurity so that everyone around the world can donate and thus benefit from their research.</p> <p>I'd love some research (survey) to be done to show that connecting with support from multiple birth clubs can make a difference to coping skills and mental health of the parents as there is evidence that this happens generally in the community when connecting with support groups but focussed evidence would be great.</p> <p>There are numerous other subjects suggested by others after a quick question to clubs yesterday, it'd either be great to be pointed to relevant research or have thought applied to how we could look at them as they are concerns of parents.</p> <ul style="list-style-type: none"> • Single parent support • Social isolation, financial hardship, postnatal anxiety (not just depression), accident and twins (safety issues). • Toddler/pre-schooler behavioural issues specific to twins; i.e. jealousy, aggression, fighting to be 'top dog'. • Speech development • Separation anxiety in babies/toddlers <p>Disciplining twins and use of the reward system. From experience rewarding one twin comes across as a punishment to the other as they are doing the same thing, hitting the same milestones at the same time.</p>
Multiples of America	We always are interested in partnering with other countries on research topics. We welcome ideas from others that we can elaborate on.



Join us on Facebook

ICOMBO ON FACEBOOK

ICOMBO public Facebook page:

<https://www.facebook.com/InternationalCouncilofMultipleBirthOrganisations?ref=hl>



We are gaining more interest from individuals around the world. Have you taken a look and “liked” the page?

Do you have any information you would like to see posted on this page? If so, please contact Monica at chair@icombo.org

ICOMBO also has a members-only closed group on Facebook. The concept behind this group is so that members can discuss issues about their organisations with some privacy, rather than post comments and questions publically. There are up to 4 or 5 individuals from each of our member groups who are members of this ICOMBO Facebook group. For more information, please contact Monica at chair@icombo.org

ICOMBO Board Members

- ◆ Monika Rankin, Australian Multiple Birth Association, Chair
- ◆ Susan J. Griffith, Multiples of America
- ◆ Tiffany Wimberly, Multiples of America
- ◆ Terri Gillis, Multiples of America
- ◆ Kimberley Weatherall, Multiple Birth Canada
- ◆ Donald Keith, The Center for Study of Multiple Birth
- ◆ Keith Reed, Twins and Multiple Births Association, UK
- ◆ Christine Disselkamp, ABC Club, Germany
- ◆ Pat Preedy, Twins and Multiple Births Association, UK



Do you have organisation or event news to share?

*We want to hear what is happening in your organisation! Articles are welcome for the next edition of the ICOMBO newsletter. **Deadline: March 1st, 2016***

Send to: vicechair@icombo.org

And The Survey Said.....

The ICOMBO Congress was almost a year ago now, and we thought it might be a good time to reflect on our successes (and challenges) since that meeting. We surveyed attendees and here is what they had to say.

Contributors:

Twins and Multiple Birth Clubs Czech republic: Klara Vitkova Rulikova, Chairperson

Twinspiratie: Suzanne Lagerweij

Finnish Multiple Births Association: Ulla Kumpula, Executive Director

Multiple Births Canada: Kimberley Weatherall, Executive Director

Fédération Jumeaux et Plus: Emma Guyot, Assistant Secretary

Tamba: Keith Reed, CEO

Multiples of America: Kim Ozark, Chairperson

In the past year, what has been your organisation's greatest success?

We helped the first quintuplet family in the Czech Republic. We participated in shooting the time-lapse material about this family presented in Czech television (thirteen-episode series) and on the Congress Twins 2014 in Budapest. We started the cooperation with Ministry of labour and social affairs. We organized the meeting of twins and multiples and we have created a record number of multiples in one place (152 pairs of multiples is a Czech record).

Twins and Multiple Birth Clubs Czech republic

Writing articles, answering emails from parents asking for advice. Main topics were: school separation and sleeping problems.

Twinspiratie

We organised a big carnival for multiple birth families (Twins and triplets carnival) in an amusement park. It was a great success, as we had about 1600 multiples or their family members there.

Finnish Multiple Births Association

Received a Leadership Grant for \$5,000 to help cover the expenses of a Retreat where the Board and ED were able to do some planning for the next few months in person. New Blog website was developed for Multiple Moments - we are slowly moving our magazine to an online Blog format to save time and costs in producing it. We are almost ready to launch it live but for now only Members have access to it. Welcomed 3 new Chapters in locations across Canada. Radio Public Service Announcements through Bell Media generated increased awareness of MBC (all work was done in-kind by Bell Media saving us thousands of dollars). Successful 2015 National Multiple Births Awareness Theme: "Twin to Twin Transfusion Syndrome (TTTS) - Early diagnosis can save lives." (more info on our website at: <http://multiplebirthscanada.org/index.php/about-us/national-multiple-births-awareness-day-may-28th-2015>).

Multiple Births Canada

Meeting the Education minister board to speak about multiples needs regarding school.

Fédération Jumeaux et Plus

Changing national commissioning and inspection frameworks to explicitly include multiple pregnancies.

TAMBA

Multiples of America completed its rebranding with a newly redesigned website. Not only do we have a new trade name, new logo, newly redesigned magazine Multiples of America's Notebook, and now we have a new website. It has taken four years from start to finish and we are very proud of our new look and new inclusive feel.

Multiples of America



And The Survey Said...continued

In the past year, what has been your organisation's greatest challenge? How does your organisation plan to overcome this challenge or how has your organisation overcome this challenge?

We asked for money from the East Europe Foundation for cooperation in this region, but we weren't successful. We tried to persuade Ministry of labour and social affairs to change the discrimination of families with twins by the amount of money during maternity leave (mothers of twins get the same amount like they have only one child). We need more employees for caregiving in the families with handicapped twins or the socially excluded families with twins or triplets and for administration and fundraising.

We will try to ask other foundations for money for international cooperation and changing the good experience. We would like to use media and to engage the public to press on Ministry of labour and social affairs to perceive and reflect the special needs of family with multiples. We will try to use the special programs for unemployed persons with the aim to receive new members of our working team.

Twins and Multiple Birth Clubs Czech republic

To find time to translate my articles and my book from Dutch to English. To get health services to invite me to come over for workshops for parents of multiples.

I am actively looking for people to help me translate my work. Also I planned to contact health services to see how we can have workshops organised.

Twinspiratie

To get finance for our work and events.

We asked business companies to give money for organising the carnival. It succeeded quite well, as we made a nice visual image for the event and we had clear amounts of money for every way to join. We also try to attract persons with anniversaries to ask their guests to give money to us (instead of flowers and gifts). We happened to get one person to do this and now we use this as an example with a nice article of him in our newspaper. We hope other people would do the same! We are also planning to apply for project funding to the Finnish Slot Machine Association. I am preparing that project at the moment.

Finnish Multiple Births Association

Finding funding and volunteers. It has been an ongoing struggle to receive outside funding or donations, which means we rely too heavily on membership fees.

We are looking at alternative ways to raise funds like lowering our Direct Member fees to \$10.00 to match what a member pays through one of our Chapters to belong. We are looking at increasing advertising on our website, our new MM Blog and in our E-News that we send out and we are looking at finding corporate sponsors. As always we are trying to get grants through companies and foundations, but we are always getting rejected as we are not able to compete with some of the bigger charities, most often those that are based on health issues.

Multiple Births Canada

We are trying to maintain our number of volunteers and involved families.

We will use the new website, an on line form and courses for volunteers

Fédération Jumeaux et Plus

Moving offices and recruiting new staff.

We found bigger offices and carried on advertising for new staff.

TAMBA

Membership numbers have declined.

We are developing a new growth initiative that will assist both our local clubs and our organization. We are looking at ways to think outside the box to attract new members using social media and webinars to add value to membership in our organization.

Multiples of America

And The Survey Said...continued

What exciting projects has your organisation got planned for the coming year, and how will you undertake them? (I.e. funding, planning, people resourcing)?

As previously mentioned we will try to use the special programs for unemployed persons with the aim to receive new members of our working team. We want to work with the media and public to exert pressure on the Ministry of labour and social affairs to make changes in the family policy with consideration of multiples families. We would like to use European social fund to start publishing the Twins magazine

Twins and Multiple Birth Clubs Czech republic

At the moment we have a net project with our college associations (Single parents, rainbow families etc). The aim of this project is to get changes to our social policy laws for example and increase knowledge of different type of families. This project will end in 2016 and we are planning to apply for a new project, as it has been so useful. We have a contest for our clubs; who will tell us the best ways to increase the number of members in clubs. The club with the best idea will get 300 euros. Our committee will also decide soon on the new project to apply for I 2016.

Finnish Multiple Births Association

The overall focus for the next year is to find funding and additional help by recruiting more volunteers. Right now the focus is on transitioning staff members. I, as the ED, have given my notice as of October 31st and so right now the focus is to find someone to take over the office duties in an Office Manager position. In addition, our AGM is coming up in October and there will be a transition between an old Board to a new Board with a number of long time Board members stepping down. Any new projects that will be taken on will be decided after that time.

Multiple Births Canada

Publishing a parenting book. Finding ambassadors (People, sport, media.etc)

Fédération Jumeaux et Plus

TTTS registry to be used by the main fetal medicine centres to be launched. Big research appeal launched to pay for these research projects <http://www.bmfms.org.uk/TAMBA-Bursaries/c-1-71.htm> New resources for lone parents, dads, grandparents and a pregnancy countdown tool. Expanding our practical helping hands scheme.

TAMBA

Our Organization just completed our year with our 55th annual convention. So we are just beginning our new year with new Board of Directors including new President, Melodie Wisniewski. We just developed a Scholarship for education of Multiples and parents of multiples so we are looking at our first awards this year. Our priority this year is growing our membership

Multiples of America



And The Survey Said...continued

For a long time, the NZMBA affiliated multiple birth clubs have been struggling to recruit and retain committee members. Has your organisation faced a similar struggle and if so, how did you manage to overcome this issue?

Our umbrella organization has a stable committee, but it is true that we have problems finding volunteers for leading the regional Twins clubs. We manage this by letting the concrete Twins club "sleep" (in the case when the leading mums are going back to work and have no time to lead this regional Twins club), but the contact details of these former active mums is still in our database and on websites. When another active mother appears in that region, the former active mum gives her advices about how she led the Twins club and helps her in the beginning. Ten years ago there were more active families who prepared program for others and create different activities in Twins clubs, but now a lot of families joins Twins clubs and wait for some entertainment or are passive. Only a few mums are helpful to organize something for others.

Twins and Multiple Birth Clubs Czech republic

My organisation grows using Facebook as a platform to share new articles on my websites.

Twinpiratie

It has been easy to get committee members for Finnish Multiple Births Association. Our clubs may have faced similar struggle, but I understood not so much at the moment. We have planned special education only for chairpersons of the clubs to tell them more about their important role in leading the committee.

Finnish Multiple Births Association

Yes, we have as well. We are now trying to cut down the job descriptions to be bare bones and recruit for smaller tasks that will not take up as much time from a volunteer as would have done in the past. We have also started to use a new Volunteer Management tool to help streamline the volunteer management process. We are just beginning with it.

Multiple Births Canada

It's a real challenge, we give support to people and offer courses and booklets.

Fédération Jumeaux et Plus

Giving clubs flexibility over how they operate (do they need a committee?), encouraging them to partner with other recruits.

TAMBA

Last year we had about 12% reduction in membership. In the United States the reduction averages about 33% so we are much less than the national average but we need to address the reduction we have experienced and look at ways to reach the newer parents of multiples and the seasoned parents with older multiples.

Multiples of America



And The Survey Said...continued

As a result of issues with retaining/recruiting volunteers the NZMBA is now facing the challenge of maintaining and supporting smaller clubs and our members who are in outlying regional areas. Has your organisation faced similar issues and if so, how have you overcome those issues e.g. merging clubs, running groups as satellites of larger clubs, etc?

As previously mentioned only three of our local Twins clubs (52) has their own board, so everything in the local Twins clubs is based on volunteers who lead the Twins club in mother centres or in nursery schools (to have some place suitable for children to meet).

Twins and Multiple Birth Clubs Czech republic

We have some clubs that have groups as satellites. We are planning to address some of our funding to clubs for that purpose in the future.

Finnish Multiple Births Association

Yes, it is hard to serve everyone well. We are doing a lot more through social media using closed Facebook groups to bring people together from across Canada and build relationships between people and be able to give more feedback/support quicker through these Groups. We have a number of specific groups for Chapter Executive from a General one, to Sales Committee Volunteers, one for Presidents and for those who offer Prenatal Classes. Unfortunately, we have watched some of the smaller Chapters fall apart and in the end close down. It is really hard to watch them close down knowing that there is a need in their community.

Multiple Births Canada

Yes, we suggest small clubs to work together. We offer technical support

Fédération Jumeaux et Plus

If the clubs can't sustain themselves then is there a need for them? Does it make more sense to put local families in touch with one another via social media?

TAMBA

This is an area that we are looking at.

Multiples of America



And The Survey Said...continued

The NZMBA has worked hard to meet the needs of our families new to the world of multiples, and is now focusing on ways to better serve those who are raising older multiples. How does your organisation (and clubs) currently support families with older multiples?

We regularly organised camps for families with older twins, but now the interest in these camps declines. We do prepare one event a year in a natural theme park for young and old twins. We help the twins students with themes concentrated on the issue of twins. Many Twins clubs regularly organize evenings for mums, which is attended also by mums with older twins and they can discuss their special problems. We prepare a booklet for teachers about how to work with twins in their class. We work in advisory roles with adult twins (or their partners) who have special problems in personal life. We also advise senior twins who can open up when they lost his/her twin.

Twins and Multiple Birth Clubs Czech republic

The information and advice that Twinspiratie supplies is for multiples aged 0-18

Twinpiratie

Work is mainly focused to families with younger multiples. We made a free booklet for parents of older multiples in our web pages (ICOMBO will get the translation into English!). I hope that we could have a support group in social media for families with older multiples one day!

Finnish Multiple Births Association

MBC is not doing anything specific in this area. We do try to have articles in our magazine that cater to the needs of the older kids and even for adult multiples when we can. We do have an Adult Multiples Support Network and Facebook Group but it is not very active.

<http://multiplebirthscanada.org/index.php/parents/support/adult-multiples-support-network>.

We do have some of our Summer Attraction Discounts for families so that they can take advantage of amusement parks, museums, etc. I think that our Chapters try to plan events that older kids could also have fun with. But I did hear the same questions from them as well on how they could better support these families. One Chapter for years planned a family camping trip with many families and only recently stopped it. The kids loved it so much that they are now holding a smaller version soon. Good luck with everything!

Multiple Births Canada

We have psychologist support. We are looking for partnership regarding driving lessons or activities for older multiples. We are yet to discuss the costs.

Fédération Jumeaux et Plus

Online webinars, written resources, helpline.

TAMBA

We are looking at ways to improve the value of membership in our organization. We have just recently approved starting an educational scholarship for parents of multiples and for multiples themselves. We hope this will attract parents of older multiples to want to join our membership or will keep members with older multiples.

Multiples of America

*A big thank you to Ainslee Jacobson
for her work on this survey!*

