



**International Multiple Birth
Awareness Week**

*Research With Multiples
Benefits Everyone*

November 5 - 12th, 2018

News From Around The World

October 2018

Special Edition

Multiple Birth Awareness Week 2018



ICOMBO

INTERNATIONAL COUNCIL OF
Multiple Birth Organisations

Highlights In this edition:

<i>Chairperson report</i>	<i>page 2</i>
<i>Multiple Birth Awareness Week</i>	<i>pages 3-4</i>
<i>Book Review</i>	<i>page 5</i>
<i>The Value of Research</i>	<i>page 6-9</i>
<i>Board Member Profiles</i>	<i>page 9-11</i>



Chairperson Report

Monica Rankin

Welcome to our special edition of the newsletter, featuring International Multiple Birth Awareness Week. IMBAW is held every two years and features a different theme each time. The chosen theme draws attention to a particular aspect of our Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples. We use IMBAW to stimulate international discussion and action around the chosen theme.

This year, we are promoting the benefits of research to multiple birth families, and also the benefits of involving multiples in research projects. “Research with multiples benefits everyone”.

Twins and multiples provide a unique opportunity for researchers. To quote Twins Research Australia “Twins are special to research as they help us to tease apart the effects of nature (genetics) and nurture (environment) on our health.” Researchers are able to identify traits, characteristics, disorders and illnesses and determine how likely it is that they are caused by genetics, the environment or a combination of both.

Twins benefit from being involved in research projects – the twins will learn more about

themselves, they may be involved in research that requires them to participate in health tests such as sight or hearing tests, and they will benefit from being part of something big – that joining forces in a research study will make a difference.

Many of our multiple birth families would not be here without the benefits of twin research. The work that many people have done, and continue to do, has improved the outcome for families in many ways – from fertility assistance and care of preterm infants through to care of the older people in our community. We have learned about speech and language, educational issues and behaviours of individuals – what makes a person smoke or take drugs? Is religion genetic or environmental?

During International Multiple Birth Awareness Week, we will take the opportunity to look at many different areas where twins and multiples have been involved in research and also at how the research has been of benefit to our families.

Regards
Monica

ICOMBO ON FACEBOOK



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

Why Multiple Birth Awareness Week?



Multiple Birth Awareness Week is held every second year internationally and many countries also have their own national events every year at varying times. A key focus of the week is to educate communities and professionals about the unique challenges of the world of twins, triplets and higher order multiples. It is also a chance to celebrate the joy of parenting multiples and what we can learn from them.

It may seem a bit of a strange to have a 'Multiples Awareness Week' but so many people think twins and higher order multiples are cute, or sometimes freaks of nature. They don't appreciate the challenges faced, apart from them just being "double trouble", and no it is not the same as having two kids close together! We think it is important to spend some time raising awareness because the difficulties faced by families with multiples are often 'hidden' from public view. Greater awareness of these difficulties might mean that families might get more research, support and understanding, or at least kinder words when out in public trying to wrangle multiples.

Multiple birth families are faced with increased mental and physical health risks that include high-risk pregnancies, premature birth, higher needs, pre-and postnatal depression, social isolation, financial hardship, schooling issues, identity problems and strains on family relationships. Getting sufficient sleep is often a challenge and the logistics of feeding, clothing, and bathing multiples are tricky. This can mean that the babies experience less one-one time cuddling and being spoken to by their parents. As a result, there are higher rates of parental guilt and despair and post-partum depression for both mothers and fathers. Additionally, the rates of divorce are much higher.

So this week is just about opening up the conversation. Families with multiples are at higher risks of the above issues and what can we do about it? Research (the theme of this year's Awareness Week) is vital to both understand the risks and look at interventions and the support needed to improve outcomes for both babies and parents. In addition research with multiples can provide so much information that is relevant to the wider population but it is important multiples are not exploited as they have been in the past (e.g. Josef Mengele's twin experiments and Three Identical Strangers). Support, especially in the first six months, but even right through to the challenging teenage years is vital to the health of every family member be it parents and other caregivers plus siblings as well as the multiples themselves. Research can help us understand what support is needed and what is most

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Twin and Multiple Birth Research

Nancy L. Segal, Ph.D.

Professor of Psychology and Director, Twin Studies Center

California State University, Fullerton

nsegal@fullerton.edu

drnancysegaltwins.org

Twin research takes place at two levels. First, there are studies that address the unique concerns faced by many twins and their families. Twins wonder if they should head to college together, participate in the same sports or have the same friends. Parents want to know if their twins should be enrolled in the same classroom, should be dressed alike or play the same musical instrument. Research concerning these issues and others is more vital now than ever before, given that twinning rates are increasing in so many nations. Second, many researchers apply the classic twin method to learn the extent to which our behavioral, physical and medical characteristics are shaped by genetic and environmental influences. Simply by comparing the degree of similarity between samples of identical and fraternal twin pairs, scientists have learned so much about who we are and how we got that way. Many developmental questions still need answers and twins remain the best route to their discovery.

BOOK REVIEW – *TWIN MYTHCONCEPTIONS*, by Nancy L. Segal Ph.D.

Review by: Monica Rankin

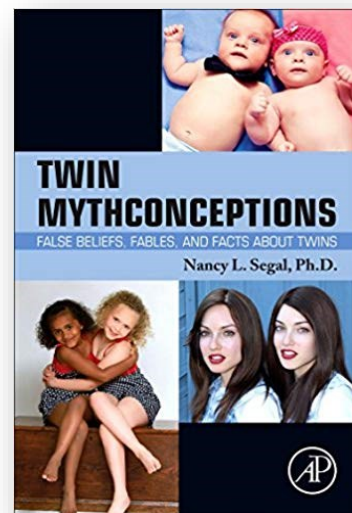
I have just finished reading this book, and it is an excellent preparation for our Awareness Week 2018. Nancy Segal is a renowned psychologist specialising in the study of twins. Part of the book dedication reads “For twins, triplets, and more who do so much for science just by being themselves” and this reveals the importance of twins and multiples to the research community.

Nancy looks over 80 different myths, misconceptions and beliefs about twins and shows how twin research can support or debunk them. For each premise, she provides a short response and then explains in detail the reason for this response. In each case, the reasoning is supported by research. For many responses, Nancy also includes personal anecdotes – about herself or about twin families she has encountered.

Why did Nancy write the book? “Mostly, I wrote *Twin Mythconceptions* because of the abundance of misinformation and misunderstandings regarding twins. This book is for anyone who has ever wondered why identical twins show similarities and differences, which couples are likely to have twins, if separating twins at school is a good idea, or if females with twin brothers are different from females with twin sisters.

Twins, families, researchers, physicians, and anyone with a taste for multiple birth facts and figures should find interesting and meaningful material.”

As a parent of twins, with a passion for twins and multiples, and their related research, I found this book to be an excellent read. It was easy to read, with explanations in plain speaking English, that the lay person can understand. For those who want even more depth, Nancy provides an extensive list of research papers that cover every topic. I am sure I will be referring to this book often as a reference tool.



[Purchase at Amazon](#)

The Value of Research

One of the key objectives of ICOMBO is to: “Promote and conduct projects and research regarding multiple birth development, care, and education.” Research is a key focus for us this year and is the subject of this year’s International Awareness Week in November. We are also about to launch a survey to help us understand more about the needs of parents and multiples themselves when it comes to participations in research. The result will be a set of criteria that clearly explains what families and multiples want from the experience. It should hopefully help to move us on from families and twins being subjects of research to being supported by the research itself. Research with multiples can potentially have huge benefits for families with multiples and also the wider community through the understanding of wider aspects of human health and behaviour. So let’s look at various aspects of research about and with multiples.

Understanding More About Multiples

Hopefully, through scientific study, we can increase our understanding about multiples from conception through to development into adults. In addition to greater understanding of multiples this type of research will also provide information to guide decisions as we parent our multiples. Here are a few things happening in this space at the moment:

- ◆ Scientists are learning more about the different types of twins, beyond just fraternal and identical, but there is still more to uncover. For example, the theory is that identical twins occur when one egg is fertilised by one sperm, and then divides and splits within two weeks of conception. The later the split, the more likely identical twins are to share structures such as the placenta (two thirds of identical twins) and the inner sac (1% of identical twins, also known as ‘MoMo’, the only twins who can touch each other in the womb). However, no one has ever seen identical twins being formed under a microscope, so we don’t know for sure what really happens or when. Indeed, there is an alternative hypothesis that all identical twins split very early (at the two-

cell stage) with a proportion then fusing back together within a few days. For more interesting facts see the full article written by Associate Professor Jeff Craig, Deputy Director of Twins Research Australia: <https://www.twins.org.au/news-and-events/blog/251-the-fascinating-and-diverse-world-of-twin-pregnancy>. Or you can read full research paper – published in the American Journal of Obstetrics and Gynaecology written by Jeff Craig, Helen McNamara, Stefan Kane and Mark Umstad. Read the full free-access paper with comprehensive diagrams of the many different types of twinning here: https://www.researchgate.net/publication/283516837_A_review_of_the_mechanisms_and_evidence_for_typical_and_atypical_twinning

- ◆ Some interesting research happening in New Zealand to look at differences in DNA between identical twins that may be useful for forensics. Rebecca is investigating DNA methylation, a modification of the DNA molecule that can change how genes are expressed but not their underlying DNA sequence: <https://www.newsroom.co.nz/2018/03/30/99744/to-catch-an-evil-twin>
- ◆ The issue of twins together or separate at school has been debated for a long time and some schools do enforce separation. A recent study from Goldsmiths, University of London, finds no strong evidence that putting twins into different classes at school is better for them academically. This is the case for both identical and non-identical twins. It says there should be no strict rules on separating twins, and it should be left to the youngsters, their parents and teachers to decide what is best. Further information on the study can be found here: <http://www.bbc.com/news/education-43821974>

It is also important to remember that academic achievement is not necessarily the main factor considered for separation. We need to understand more about the psychosocial outcomes for children with separating vs being in the same class, the dynamics of their relationships, emotional wellbeing and achievement. Ultimately it is an individual choice and based on what will benefit the children the most.

Studies to Improve Multiple Pregnancy Outcomes

Multiple pregnancies are higher risk than a singleton pregnancy and it is critical that research is conducted to improve pregnancy outcomes. Data from the UK shows multiple pregnancies make up only 3 per cent of all pregnancies but contribute to 6.5 percent of stillbirths and 13.7 percent of neonatal deaths. The data in other countries does vary, in part due to different criteria for the gestation at which a stillbirth is recorded, but for the most part it is very similar. Almost half of multiple births are premature and this is a main contributing factor to the high death rate. Surviving preterm babies often face neurological damage and disabilities (for example, twins are 6x more likely to have cerebral palsy than singletons). There are a number of areas where research has been lacking and these include twin growth charts, reducing premature birth and looking at the most effective treatments for TTTS in the short or longer term. Hence Tamba has been running a number of research projects including the most recent 'The Big Research Appeal' which is raising money for the largest research programme of its kind in the world.

About five years ago Tamba launched the Beanstalk Appeal to raise money for research to produce the world's first accurate twin pregnancy growth charts. These took a little longer than they expected to get onto hospital systems but in July 2017 the first twins were born who had been measured using the new charts – a significant landmark in medical history! These charts have become widespread in the UK and are slowly spreading to other parts of the world.

The second step was the creation of a UK Twin to Twin Transfusion Syndrome (TTTS) Registry to record all cases of TTTS in order to gather key data to improve clinical practice, measure short and long term outcomes and improve treatment options. A comprehensive set of data is being collected to help build a true picture of TTTS cases in the UK, the survival rates and outcomes. Crucially, a national UK Registry will provide a tool to assist the improvement of clinical skills and practice and therefore help to provide better patient care at a local, regional and national level. It will also establish a platform to

allow long term follow up of TTTS survivors at a national level showing the longer term neurodevelopment outcomes. The data will also be invaluable for future ongoing research into TTTS, for example, the longer term consequences of individual treatments. Eventually they hope to replicate this model internationally.

The third step is the Big Research Appeal and so far Tamba, together with the British Maternal & Fetal Medicine Society (BMFMS), have commissioned five crucial clinical studies:

1. Single intrauterine fetal death in monochorionic twin pregnancies
2. Neurodevelopment outcomes in twin pregnancies with complications, including twin to twin transfusion syndrome (TTTS), single intrauterine death, selective intrauterine growth restriction, twin reversed arterial perfusion sequence (TRAPS) and twin anaemia polycythemia sequence (TAPS)
3. Prevalence of monochorionic monoamniotic (MCMA) twin and triplet pregnancies and to compare birth outcomes and clinical management of these pregnancies
4. Emergency Cerclage in Twin Pregnancies at Imminent Risk of Preterm Birth
5. Examination of the Myometrial Transcriptome in Twin Pregnancies

Tamba is now currently seeking funding to support two further studies.

In addition to this, Tamba's research programme has led to a twenty-fold increase in the number of fetal medicine centres publishing research papers on the complexities of treating multiple pregnancies. This demonstrates that the multiple birth community can make a difference and achieve great things.



<https://www.tamba.org.uk/big-research-appeal/about-phase3>

Studies Using Twins

In addition to research to specifically benefitting families with multiples ICOMBO has an interest in wider research projects that involve multiples as study 'subjects'. It is important that we ensure that we protect the interests of multiples and ensure researchers understand all the implications of such studies. With their similar genetic makeup, twins represent an ideal opportunity to study health and behaviour issues. Differences between identical and fraternal twins (who on average share 50% of their DNA) reveal interesting insights and provide the optimal way to tease genetic effects from the environmental effects. Studies can also provide scientific insights into genetics conditions such as diabetes, heart disease, and obesity, as well as the effects of alcohol and tobacco use. By identifying the genetic components of these health problems and others through twins research, it is possible to develop early interventions and treatments.

Some of the interesting findings from recent research include:

- ◆ Twins were the subjects in a recent study of substance abuse in teens: "Parents spend a lot of time worrying about the influence of peers on teen substance use. A new study examines if there is a genetic component that drives teens' desire for risk taking and novelty. A key finding revealed genetic influences that are unique to the growth in substance use. With each passing year, genetic differences between individuals become more and more important in explaining why substance use increases in some adolescents but not in others." <https://www.sciencedaily.com/releases/2018/04/180425093758.htm>
- ◆ The OATS aims to find out what influences memory and thinking as we age. It investigates environmental influences such as lifetime physical and mental activity, socioeconomic environment, and nutrition. It also investigates how biological factors such as hypertension and antioxidant levels interact with genes to influence brain ageing. Since, over time, the expression of genes varies depending on different influences in the environment, by studying twins, OATS aims

to determine which influences on the ageing process are genetic, which are environmental, and how the two interact. <https://cheba.unsw.edu.au/project/older-australian-twins-study>

- ◆ Surveying identical twins is allowing researchers to identify the separate genetic and environmental factors that may contribute to acne severity. This twin study further supports that there may be a genetic phenotypic link, though social and environmental factors may also have an influence in the disease process. <https://dermatologyresearchnews.com/acne/an-acne-survey-from-the-worlds-largest-annual-gathering-of-twins>
- ◆ A test to diagnose cerebral palsy at birth, which could allow infants access to critical early interventions, is one step closer thanks to research with twins. It is also especially relevant for the multiples community as cerebral palsy is more common in twins and triplets (and possibly higher order multiples but there is insufficient data to know the rates) than singletons. There are at reasons for this: Multiple pregnancies are more likely to result in premature delivery. Premature birth often results in low birth weight new-borns. Both are risk factors for Cerebral Palsy. <https://www.mcri.edu.au/news/research-make-early-diagnosis-intervention-possible-cerebral-palsy>
- ◆ Many interesting insights are being provided from study of identical twins where one went into space for a year while the other remained on Earth. There have been many reports of this study, although some of them have been rather misleading including that Scott Kelly's DNA itself had changed. However, what researchers observed was changes in gene expression, which is how your body reacts to your environment. These changes were probably within the range for humans under stress, such as mountain climbing or scuba diving. It is not surprising that spaceflight affects how much expressing certain genes do, particularly those involved in immune function, DNA repair pathways, and bone growth. <https://www.space.com/40007-astronauts-scott-mark-kelly-still-identical.html>

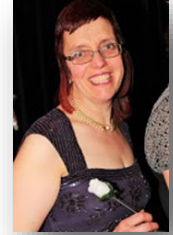
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Continued.... The Value of Research

- ◆ Following on from the space study two experienced mountaineers are in the middle of a month-long expedition to Mount Everest, while their twins stay at sea level. The primary goal is to search for possible changes in gene expression as a result of the stressful environment at high altitude. <http://www.sciencemag.org/news/2018/05/two-mountaineers-are-trying-recreate-nasa-s-twin-study-mount-everest>

The world of research on multiples is fascinating and we never seem to stop uncovering new insights!

*Special thanks to Carolyn Lister for her article on **The Value of Research***



Carolyn Lister ICOMBO
Board Member

This edition includes additional board member profiles. We hope you have enjoyed getting to know the board members who are currently serving our organisation.



Abelone Glahn

Board position: Member

Why are you on the ICOMBO board?

I have been a member of ICOMBO since I discovered the international work for and about twins at my first attendance to ISTS in 2001 in London. In Spain during 2017's Congress, I thought it might be the appropriate time for a representative of the northern part of Europe to join. We have some experiences in working together in Norway, Sweden, Finland and Denmark, which might be of interest for other countries.

What do you want to achieve?

I would like to contribute with the experiences I have found through the work I have completed in Denmark. Hopefully it will help ICOMBO and ICOMBO members. One area I would like to see ICOMBO explore is the ethics around fetal reduction.

What is the name of the multiples club(s) to which you belong?

I don't belong to an organisation. I am a private twin mother and journalist, running the community around www.tvillinger.com and the advice-gathering / crowdsourcingsite at www.shareyourtwininterest.com

What roles have you had or do you currently have in your local/national club?

Founder

Where do you live?

At the island Falster 125 km south of Copenhagen in Denmark in an old school at the countryside.

What type of multiples do you have (twins/triplets, ID/fraternal, age, gender, etc) and any siblings?

MZ twin boys, now age 27, sister age 29, and three additional children at age 32, 36 and 38.

What do you do in your paid job (if you have one)?

I am an independent communication advisor and journalist with my own company; and, author of nonfiction books. Amongst my books are 5 about twins, adult twins and twin loss.



Kimberley Weatherall
Board Position: Past Chair

Why are you on the ICOMBO board?

I joined the ICOMBO Board in 2007 during my first-time attendance at an ICOMBO / ISTS Conference in Belgium, representing Multiple Births Canada. I immediately took on the position of Chair until stepping down in 2012, taking on the role of Past Chair. I joined the Board with the hope to help move the organization forward, to bring all national organizations supporting multiple-birth individuals and their families together and to facilitate more sharing of information and support internationally.

What do you want to achieve?

Currently, I am acting more in a supportive and guidance capacity on an as needed basis. However, I would like to see the ICOMBO Board continue in its role of bringing together and supporting the work of the other national multiple-birth organizations worldwide. With new technologies available to us it makes it possible now to learn from and share each others' successes. It is also important for ICOMBO to be the leading organization internationally in creating awareness around the unique needs of multiple-birth individuals, their families and those who support them.

What is the name of the multiples club(s) to which you belong?

Multiple Birth Families Association of Ottawa-Gatineau, a member of Multiple Births Canada.

What roles have you had or do you currently have in your local/national club?

I am currently active at the international level only as my twin daughters are now 31 and my time and attention has been moved on to other interests. In the past (1987 – 2010) I have held many volunteer positions at the local and national levels including (and probably many I am forgetting): Sale Coordinator (local), Christmas Hamper Coordinator (local), Director of Volunteer Development (national), Director of Fund Development (national), Charitable Status Liaison (national), Conference Chair / Coordinator for many annual conferences (national), Board Vice Chair (national) Board Chair (national) and Past Chair (national). I also held the part-time paid position of Executive Director for Multiple Births Canada from 2010 – 2015.

Where do you live?

Ottawa, Ontario, Canada.

What type of multiples do you have (twins/triplets, ID/fraternal, age, gender, etc.) and any siblings?

Monozygotic twin girls aged 31.

What do you do in your paid job (if you have one)?

I am the owner of Beyond Your Office, a business offering online business support in a virtual capacity to consultants, entrepreneurs, non-profit organizations, health care professionals and other small business owners in Canada and the US who offer a very wide range of products and/or services.





Terri Gillis

Board position: News Letter Editor/Publisher

Why are you on the ICOMBO board?

I enjoy volunteering and meeting other parents of multiples from around the world. As a Past President of Multiples of America, I hope I bring knowledge and value to the table when looking at how we share best practices and share research efforts.

What do you want to achieve?

I want our organization to achieve greater recognition within the multiple birth, research, and medical communities. We can do this by leveraging knowledge across our ICOMBO footprint.

What is the name of the multiples club(s) to which you belong?

Multiples of America (also known as the National Organization of Mothers of Twins Clubs, Inc.)

The Florida Organization of Mothers of Twins Clubs

Greater Orlando Mothers of Twins and Triplets Club

Flamingo Mothers of Multiples

What roles have you had or do you currently have in your local/national club?

Local and State – I have served in almost all capacities including President. Currently I hold the roles of Executive Secretary at the State level. National – I currently serve as Meeting Planner for Multiples of America and have previously served in the following board positions: Membership VP, Secretary, Executive VP, President, and Advisor.

Where do you live?

Flagler Beach, Florida. (On the northeast coast of Florida in the United States of America.)

What type of multiples do you have (twins/triplets, ID/fraternal, age, gender, etc) and any siblings?

Identical Twins Daughters who will be 45 years old this December.

What do you do in your paid job (if you have one)?

I recently retired after 47 years with SunTrust Banks where I managed the day to day design and implementation of compensation programs/systems.

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: January 30, 2019

Contact us at newsletter@icombo.org