ICOMBO
INTERNATIONAL COUNCIL OF
Multiple Birth Organisations

The International Society for Twin Studies (ISTS) and ICOMBO

Welcome you to join us in Budapest

11-14 November 2021
Online & in person

Gold sponsor:
CAMBRIDGE UNIVERSITY PRESS

News From Around The World

October 2021

Chairperson Report

Monica Rankin

As I write this article we are still grappling with the covid pandemic across the world. I am in lock-down in Melbourne, unable to travel further than 5km from my home. We were supposed to be celebrating the wedding of one of my twin sons in November but due to covid restrictions they have postponed the wedding until 2022. I am sure many of you have similar stories. Who would have thought, when we last met in 2017, that we would all be living this way?? I often find it difficult to comprehend.

I am busy preparing for our conference, as it is not long away now. We will have 2 half-day workshops and a business meeting during the conference. I would really appreciate if you could attend the business meeting if at all possible, and, the workshops. It is really important as these are the opportunities for you to have a say in how our organisation is managed, and what our direction will be for the next few years. This is a great opportunity for many people to attend – the cost is free and you do not have travel and other expenses.

You just need to log into your computer at home to participate. You can have more than one person from each organisation register for the conference, as long as they are on your executive committee.

Please make sure that each person registers as that assists us to determine how many people attend. If you are unable to participate at the time the sessions are held, you can still register as you can listen to the presentations at any time over the following month.

Further information about the conference can be found in the newsletter.

Looking forward to seeing you all online, and talking in November,

*The International **Council of Multiple Birth Organisations (ICOMBO)** is a voluntary organization whose aim is to raise awareness of the unique needs of multiple-birth infants, children, adults and their families promoting their health, education and welfare.*

ICOMBO Quick Links:

Home page: ICOMBO | International Council of Multiple Birth Organisations

Research: Research | ICOMBO

Congress Quick Links:

2021 Congress: TWINS2021 congress - Budapest

Congress Registration: Twins2021 - Registration and abstract submission

19th International Congress - Budapest and Virtual

ICOMBO AND UPCOMING CONGRESS UPDATE

The 19th International Congress on Twin Studies promises to deliver an impactful Congress for attendees who opt to attend in person or online this year. The online option which is free, along with four different time tracks, ensures this year's conference is more accessible than ever. Save the dates and register today to reserve your spot.

TWINS2021 congress - Budapest - For more Congress information go to their home page.
Twins2021 - program - Check out the four time zones on the left of the page to view each schedule.
Twins2021 - Registration and abstract submission - Register for the Congress.

- **ICOMBO CONFERENCE WORKSHOPS**

ICOMBO is hosting 2 workshops at the conference, there are 2 half-day sessions on the first two days. Here we will discuss a range of topics. If you would like to present anything to the rest of ICOMBO, please let me know as soon as possible at chair@icombo.org. I would like to know the name of the presentation and a very short paragraph to describe what you are talking about. I will be preparing an agenda for the workshops in the next couple of weeks.

- **NOMINATIONS FOR ICOMBO BOARD POSITIONS**

We would welcome new faces on the ICOMBO Board. A nomination form is attached. We are looking for:

- A social media person, who would be interested in maintaining our Facebook page and perhaps other social media in the future.
- Someone who would be interested in keeping our membership records, and seeking out new organisations that may be interested in becoming part of the ICOMBO family.
- Someone interested in editing and publishing our newsletter.
- Any person who believes they can add value to ICOMBO, as a general board member.

A nomination form is attached, if you are interested in a position, please email chair@icombo.org or complete a nomination form and send it to chair@icombo.org

So you are attending your first Congress....

As I prepare to virtually attend this year's Congress, I can't help but think back to my first Congress in 2012, when I attended in person in Florence, Italy. At the time I was the Advisor for Multiples of America and I was asked to attend Congress with the current President and Dr. Susan Griffith, another active ICOMBO member. We travelled to Rome, caught the train to Florence, and spent the next three days networking and attending workshops hosted by ICOMBO and ISTS.

As a first time attendee, it was a little overwhelming to figure out which workshops to attend. As a non-medical professional, I found some of the topics to be overwhelming at first glance. But what I quickly learned was no matter how technical a session was, I could gain valuable insight by attending the workshops on topics that were important to me or the organization I represented. For example, by attending sessions on Twin-to-Twin Transfusion Syndrome (TTTS), I was able to gain additional knowledge on this syndrome which helped me understand what many of our members had gone through to ensure a safe and healthy birth for their multiples. I was also able to network with Dr. Ruben Quintero a pioneer in the field of TTTS.

To prepare for this year's Congress, I first went to the Congress website and reviewed the program schedule after finding my time zone to ensure I marked my calendar for the right dates and times. Then I looked at each workshop and came up with a short list of workshops I don't want to miss, along with the Congress Keynote address by L. Scott Forbes, ***"The Evolutionary Biology of Twining in Humans".*** This keynote sounds like it will set the stage for the rest of the Congress. Take a look at my picks:

- **Three Twinship Myths: Setting the Record Straight** Joan A Friedman, PhD Institute of Contemporary Psychoanalysis, Los Angeles
    - *This workshop is being conducted by one of my favorite twin experts.*

- **Why Are Monozygotic Twins Different: From Genetics to Environment**, London: Elsevier. A. Matias, & I. Blickstein (Eds.) Alexandra Matias, MD, PhD University of Porto, Portugal
    - *I find Monozygotic Twin research and talks to be fascinating.*

- **Discussion: Five recent and forthcoming books on twins –** Live discussion and Q & A with the authors and editors Co-chairs: Nancy L Segal, PhD & Professor Jeffrey Craig
    - *I love panel discussions and Nancy Segal is always on point. Besides co-chairing this event, Nancy will be talking about her own book,* ***Deliberately Divided: Inside the Controversial Study of Twins and Triplets Adopted Apart****,* Lanham, MD: Rowman & Littlefield, 2021
        - Check out Nancy's book offer on pages 6 & 7 of this newsletter.
- **ICOMBO Workshops and Business Meeting:**
    - *Each one is a must as this is where our members will share topics and research among our organisation attendees. And at the business meeting, we will conduct the business of our organisation and elect new term officers.*

As I prepare for this year's virtual sessions, I cannot help but yearn for the in-person experiences of my 2012 attendance. I met ICOMBO members from around the globe, and made lasting friendships. We worked together, learned together, and experienced Florence after hours together. Truly an experience of a lifetime. And truly an experience we can plan for in the future. I hope to see you there!

Join me online this year, and begin your ICOMBO/ISTS journey. It's one you will always remember.

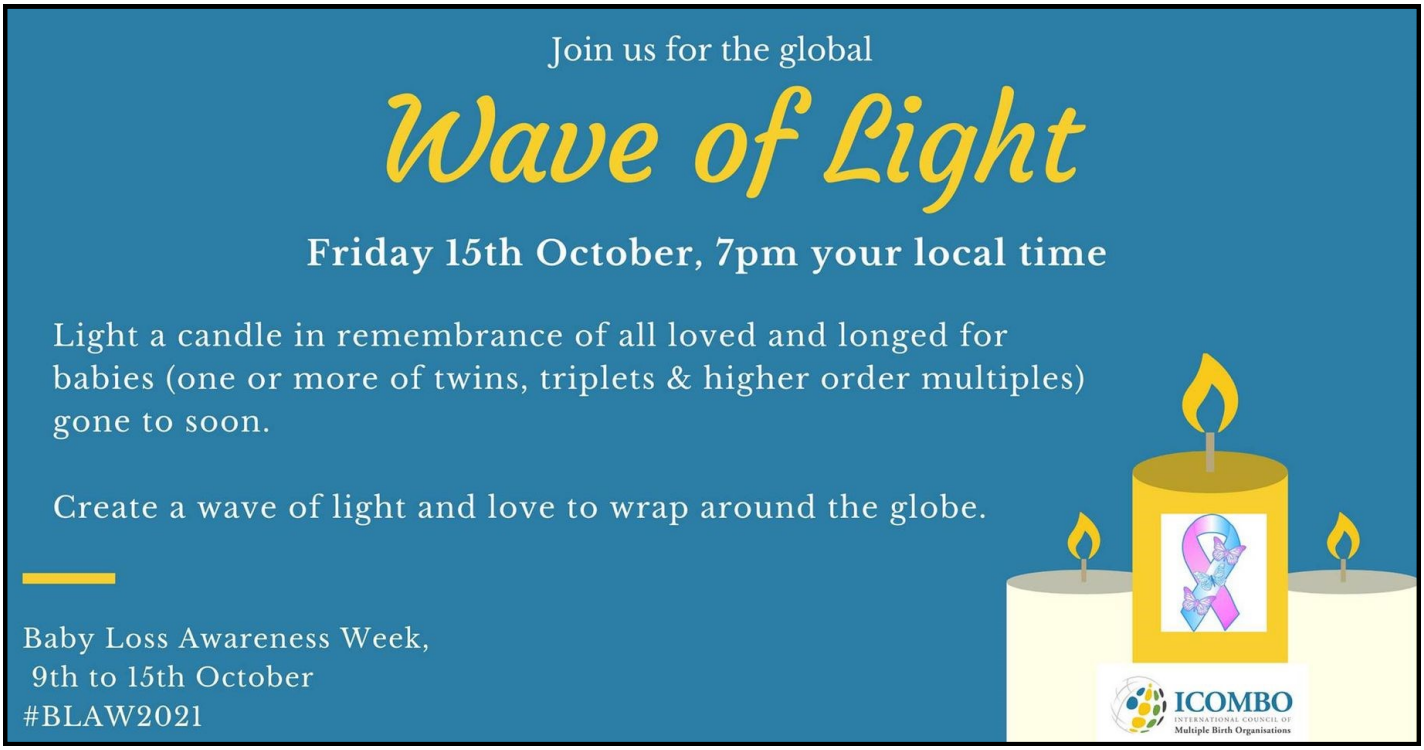
Terri Gillis
Newsletter Editor/Publisher—ICOMBO Board of Directors
Florida Organization of Mothers of Twins, President
Multiples of America, Past President

ICOMBO - Look at our Growth!

As a world-wide organisation, we continue to grow and show our diversity as a support group for multiple birth organisations. Through an ICOMBO membership we can share ideas, best practices, experiences, and have a global impact on research. Thank you members!

Current ICOMBO Members include:

- 7 individual members
- 1 professional member
- 25 organisations, from the following countries:
  - Australia
  - USA
  - Canada
  - New Zealand
  - Argentina
  - Japan
  - Rwanda
  - Liberia
  - Nigeria
  - Czech Republic
  - Germany
  - Norway
  - Denmark
  - Finland
  - Trinidad & Tobago
  - Netherlands
  - Serbia
  - Belgium
  - France
  - Spain



ICOMBO Nomination Form

DIRECTOR NOMINATION FORM 2021

The ICOMBO Board will be holding elections for all positions at the ICOMBO Business Meeting, which will be held on 14 November during the Congress.

All positions are vacant, some will be decided by election, and some by appointment, as per our constitution. If you are interested in holding one of these positions, please complete the form and return it to Monica Rankin, chair@icombo.org

The following ICOMBO Board positions will be decided by election

- Chair
- Vice Chair
- Treasurer
- Newsletter Editor

The following ICOMBO Board positions will be filled by appointment.

- Past Chair (will be filled by the previous board chairperson)
- Membership Director
- Research Director
- Social Media / Website Director

In addition, there are positions available for people who have a particular interest/skill that would benefit the ICOMBO Board. If this sounds like you, please complete the form below, writing "general" in the space for position title.

If you have any questions, please contact Monica, chair@icombo.org

NOMINEE'S DETAILS:

Title:

Name:

Address:

Phone no: (include country code)

Email:

Please complete the following declaration –

I _____ (name of Nominee) hereby seek appointment to the ICOMBO Board of Directors for the position of _____ .

CHECK AND COMPLETE AS APPROPRIATE

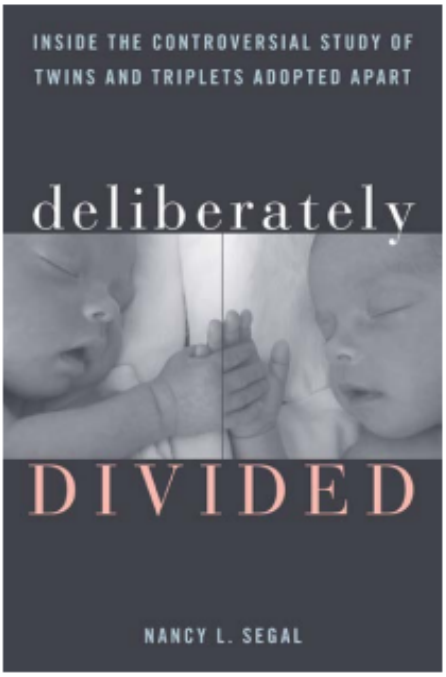
☐ I declare that I am a member of ICOMBO

☐ I declare that I am a member of:

_____

(name of multiple birth association)

Book Offer By Nancy L. Segal



ROWMAN & LITTLEFIELD

DELIBERATELY DIVIDED

Inside the Controversial Study of Twins and Triplets Adopted Apart

By Nancy L. Segal

SPECIAL OFFER

30% DISCOUNT OFFER OFF LIST PRICE

PLEASE ORDER USING THIS CODE: RLFANDF30

978-1-5381-3285-2 • Hardback • $40.00 list price (discount price $28.00)
978-1-5381-3286-9 • eBook • $38.00 list price (discount price $26.60)

About the Book

In the early 1960s, the head of a prominent New York Cit Child Development Center and a psychiatrist from Columbia University launched a study designed to track the development of twins and triplets given up for adoption and raised by different families. The controversial and disturbing catch? None of the adoptive parents had been told that they were raising a twin—the study's investigators insisted that the separation be kept secret. Here, Nancy Segal reveals the inside stories of the agency that separated the twins, and the collaborating psychiatrists who, along with their cadre of colleagues, observed the twins until they turned twelve. This study, far outside the mainstream of scientific twin research, was not widely known to scholars or the general public until it caught the attention of documentary filmmakers whose recent films, *Three Identical Strangers* and *The Twinning Reaction*, left viewers shocked, angered, saddened and wanting to know more.

Interviews with colleagues, friends and family members of the agency's psychiatric consultant and the study's principal investigator, as well as a former agency administrator, research assistants, journalists, ethicists, attorneys, and—most importantly--the twins and their families who were unwitting participants in this controversial study, are riveting. Through records, letters and other documents, Segal further discloses the investigators' attempts to engage other agencies in separating twins, their efforts to avoid media exposure, their worries over informed consent issues in the 1970s and the steps taken toward avoiding lawsuits while hoping to enjoy the fruits of publication. Segal's spellbinding stories of the twins' separation, loss and reunion offers readers the behind-the-scenes details that, until now, have been lost to the archives of history.

About the Author

Nancy L. Segal, PhD, is Professor of Psychology at California State University, Fullerton and Director of the Twin Studies Center. She has authored over 250 scientific articles and six books on twins and twin development—a recent survey placed her among the top 2% of well-cited scientists worldwide. Born in Boston and raised in New York City, she lives in southern California.

Praise for the Book

"The documentary *Three Identical Strangers* captivated viewers with the story of identical triplets who were separated at birth, studied by psychiatrists, and kept unaware of one another's existence. *Deliberately Divided* is the inside story of the history and science behind this disturbing event, told by a leading researcher and a gifted expositor."**—Steven Pinker, Johnstone Professor of Psychology, Harvard University, and author of *The Blank Slate* and *Rationality***

"Before reading *Deliberately Divided* it never occurred to me that a book on the study of twins could be a gripping drama. Yet here, Nancy Segal, herself a professor of psychology (and a twin), writes so movingly about an unfortunate twin study that deliberately left many twins to grow up apart. Was this disruption of human lives worth the cost just to learn something about human nature? I was on the edge of my seat waiting to find out what happened when the long-separated twins found each other later in life. This is one of the most educational and entertaining books on psychology I've ever read."**—Elizabeth F. Loftus, distinguished professor, University of California, Irvine and former president, Association for Psychological Science**

Read more reviews online at Rowman.com.

Book Offer By Nancy L. Segal

ORDER FORM	(Billing in U.S. dollars)	*Please send me the following book right away:*

ISBN	Title	Price	Qty.	Cost
Hardback 978-1-5381-3285-2	***Deliberately Divided***	after discount: $28.00		
Ebook 978-1-5381-3286-9	***Deliberately Divided***	$26.60	Ebooks can only be ordered online.	
			Promo Code*	**RLFANDF30**
			Shipping Costs (see below)	
			CA, CO, CT, IL, MD, ME, NY, OH, PA, TN, TX residents, please add sales tax	
			Total	

- **Discount applies to these ISBNs only | Offer expires October 31, 2022 and may not be combined with other offers.**
- **Promotional price on books** is for U.S. orders only
- **Shipping and handling: U.S.:** $5 first book, $1 each additional book | **Canada**: $6 first book, $1 each additional book plus applicable Canadian sales tax. | **International orders**: $10.50 first book, $6.50 each additional book.

FIVE CONVENIENT WAYS TO ORDER:

- ✓ Online: https://rowman.com
- ✓ Call toll-free: 1-800-462-6420
- ✓ Email: orders@rowman.com
- ✓ Fax toll-free: 1-800-338-4550
- ✓ Mail to: Rowman & Littlefield, 15200 NBN Way, P.O. Box 191, Blue Ridge Summit, PA 17214-0191

All orders from individuals must be prepaid. Prices are subject to change without notice.

Please check: ☐ Mastercard ☐ Visa ☐ Amex ☐ Personal check (make payable to Rowman & Littlefield)

Credit Card #: _____ Exp. Date _____

Signature: _____

BILLING AND SHIPPING ADDRESS:	
Name	
Institution	
Street	
City, State, Zip	
Country	
Phone	

Research News....

NEW LEADS IN RESEARCH INTO THE ORIGIN OF IDENTICAL TWINS

https://www.twins.org.au/news-and-events/latest-news/463-researchers-make-new-discoveries-about-the-origins-of-identical-twins

An international group of researchers led by Jenny van Dongen and Dorret Boomsma of the Vrije Universiteit, Amsterdam, the Netherlands has made a ground-breaking discovery that could lead to new insights into the blueprint of identical twins. The researchers found a unique epigenetic profile in identical twins. The findings represent a huge step forward in understanding identical twins. The article that details the research is titled *Identical twins carry a persistent epigenetic signature of early genome programming* and can be found here: https://www.nature.com/articles/s41467-021-25583-7

The mystery of identical twins

Identical (monozygotic – MZ) twins cause much confusion to their parents and friends and make very cute cover photos for magazines, but despite a century of amazing progress in most areas of science we still have no idea how they arise. As MZ twins appear to crop up randomly in families at a rate of about 4 per 1000 births all around the world, neither analyses of possible genetic predisposition nor studies of putative environmental exposures have cast much light on the origins of MZ twinning. In contrast we are making fast progress on understanding the biological origins of nonidentical (dizygotic – DZ) twins, which run strongly in families, pointing to genetic influences. Not surprisingly, genomic studies are proving useful in finding the genes behind DZ twinning.

The processes leading to these 2 types of twins are very different. Dizygotic twins arise after double ovulation, in which the genetic predisposition of the mother plays a major role. Identical twins arise from a single embryo that splits into two in the very stages of pregnancy and retain the same base-pair sequence of their genes. To date, it is unknown why this happens.

The main finding

Now, researchers have made an important discovery: epigenetic information in the chromosomes differs between identical twins and others. These epigenetic differences are not in the DNA code itself, but in small chemical marks associated with it. Twin registries from the Netherlands, Great Britain, Finland, and Australia participated in the study.

Professor Dorret Boomsma of the Netherlands Twin Register specializes in genetics and twin studies and spent most of her career working with twins and their relatives. Boomsma: "This is a very big discovery. The origin and birth of identical twins has always been a complete mystery. It is one of the few traits in which genetics plays no or very modest role. This is the first time that we have found a biological marker of this phenomenon in humans. The explanation appears not to lie in the genome, but in its epigenome".

Professor Bruno Reversade of the Agency for Science, Technology and Research (A*STAR) in Singapore: "This amazing finding is diagnostic, it brings hitherto unknown insights into the fabrics for MZ twinning. The next step will be to find out why this happens".

The epigenome

Around the building blocks of DNA (the DNA code) are control elements that determine how genes are tuned and how strongly they are expressed. This is the so-called epigenome. A useful analogy is how the holding the shift key on a keyboard, can make the letter "a" become capitalized "A" allowing another level of regulation on how each letter or number on the keyboard can be displayed. Likewise, DNA methylation (like pressing the shift key) controls which genes are "on" and which genes are "off" in each cell of the body. The field that studies this tuning of genes is called epigenetics.

Professor Nick Martin of the Queensland Institute of Medical Research, Brisbane, Australia adds: "This study could only have been done by an international collaboration of twin researchers. It provides an exciting new breakthrough."

Professor Jeff Craig, who works in Early Life Epigenetics at Deakin University, Australia is President of ISTS. He kindly wrote the following Question & Answer article about this exciting research finding.

Continued—page 9

Q & A of the new twin study titled "Identical twins carry a persistent epigenetic signature of early genome programming"

Q: Why was the study done?

A: To find out clues about why, how, and when, a single fertilised egg can split into identical twins within a few days.

Q: How was the study done?

A: The authors were looking for a record of twin splitting events that are 'remembered' by cells present in twins well after they are born. They knew that good candidates are the molecules that stick to our DNA that we call 'epigenetics'. Epigenetics are the molecular dimmer switches that turn our genes up and down as we develop in the womb and beyond. And we know that the experiences a developing baby experiences in pregnancy can sometimes change their epigenetic switches. The authors collected blood from thousands of twins and their parents across multiple twin studies. They then compared the epigenetic switches in the DNA of the blood cells of identical twins with those from fraternal twins and singletons.

Q: What did the study find?

A: The study found that identical twins differed in the levels at which their epigenetic switches were set, at hundreds of locations along their DNA. Many of these differences were located in genes that help different kinds of cells recognise each other and stick together only with those cells that are similar. The authors also found that they could use their data to blindly identify whether a DNA sample comes from an identical twin, albeit with limited accuracy. The authors also say their test could one day identify singletons who started off as identical twins but lost their co-twin very early in pregnancy.

Q: Did the study show what causes twinning?

A: No, the authors admit that they don't know whether their findings reflect the cause or the consequences of twinning.

Q: If the differences they observed were the cause of twinning, what would this tell us?

A: This would tell us that a combination of unknown factors, probably a combination of genetics, environment and pure chance, may be causing cells of the very early embryo to lose their ability to stick together, causing a splitting event.

Q: Tell me more about the implications of these findings for singletons who started life as a twin?

A: The study mentions that it's suspected that in almost nine out of ten identical twin pregnancies, one twin 'vanishes' very early on. And that this increases the chance of birth abnormalities such as cerebral palsy in the surviving twin. Further, it's been suggested that many birth abnormalities can be much more frequent in twins than current knowledge suggests. This study may help resolve this issue.

Q: What does the study mean for identical twins?

A: The study confirms what many identical twins already know – that they are different from same-sex fraternal twins.

Q: What does the study mean for parents of twins?

A: It means that we know a little more about the events that took place inside you and produced the miracles that are your twins.

Continued—page 10

Research News continued....

Q: What does the study mean for singletons and their parents?

A: Some singletons could have started life as an identical twin and lost their co-twin very early on. If there was a test to identify identical twins, singletons could take it. However, they and their parents would need to think about the potential trauma that the knowledge of a loss during early pregnancy could provoke before they chose whether to take such a test.

Q: Has the study produced a new test that identified identical twins and if so, will this replace zygosity tests?

A: No, the 'test' they develop is far from accurate so at the moment it's not ready for the market. In all probability, zygosity tests will always be cheaper.

Q: Does the study tell us why only humans have identical twins?

A: Actually, only human have identical twins but armadillos can have identical quads and octuplets. However, the study does not answer the question of ;why?'

Check out the following research documents at the ICOMBO Website :

https://icombo.org/school-placement-survey/

https://icombo.org/multiple-perspectives-paper/

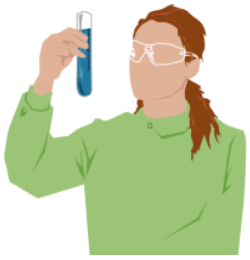
https://icombo.org/participation-in-research-survey/

https://icombo.org/priority-setting-partnership-survey/

https://icombo.org/research/post-partum-hemorrhage-in-mothers-of-multiples/

https://icombo.org/postnatal-depression-survey/

https://icombo.org/zygosity-research-articles/



International Multiple Birth Awareness Week (IMBAW)

IMBAW is a campaign to raise awareness about the issues, needs and unique realities for multiple birth families around the world. 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. 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, social stigmas, identity problems and strains on family relationships. Research, education and advocacy can contribute to enabling positive outcomes for families with multiples.

The theme for 2021 is around collaborations to build partnerships and networks between multiples/parents of multiples, support groups, researchers, medical and other healthcare professionals and other relevant organisations. We want to talk about how a multidisciplinary and collaborative approach can be beneficial for multiples and their families. The study of multiples does provide insights for the whole population, however it is also critical that research and medical advancements help improve outcomes for twins, triplets and higher order multiples, who face unique challenges from pregnancy through to adulthood.

The week is timed to coincide with Budapest 2021 - The 19th International Congress on Twin Studies. This will provide us with an opportunity to highlight some of the work that is happening around the world driving improvements for multiples and their families.

We are trying to come up with a good tagline. So far we have:

- ***Collaborating for better outcomes***
- ***Collaboration for the benefit of families with multiples***
- ***Collaboration – we're better together***
- ***Collaboration and partnerships driving change***
- ***Collaboration - we can go further when we go together***
- ***Collaboration to build knowledge and understanding***

Let me know your thoughts and any other suggestions you have.
Carolyn (carolyn@icombo.org)

The 5th World Congress on Twin Pregnancy

Synopsis of Beijing Conference

Documented by Carolyn Lister

The Joint 5th World Congress on Twin Pregnancy: A Global Perspective and the 17th Congress of the International Society Twin Studies (ISTS) was held online from the 4th to 6th June 2021 hosted in Beijing, China. The aim of the conference was to integrate international efforts on twins research and clinical management and brought together leading international experts (e.g. Ruben Quintero who developed the Quintero Staging System which is used in the assessment of patients affected with Twin-Twin Transfusion Syndrome, TTTS and Asma Khalil researcher and Professor of Obstetrics and Maternal Fetal Medicine at St George's Hospital, University of London and lead for the Twin and Multiple Pregnancy service). The main topics highlighted during the Congress were:

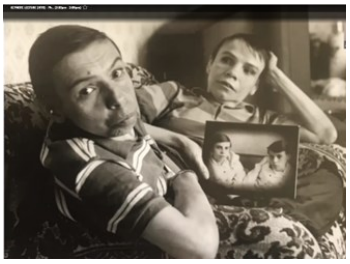
- Emerging methods in twin research
- Delivery of twins
- Care in pregnancy and labour
- Large collaborative studies in twin birth cohorts
- OMICS twin studies
- Psychological studies of twins
- Twin-related complications
- Preterm birth and prematurity

Below are just a few of the highlights. The full scientific programme can be found here:

https://www.mcascientificevents.eu/twins/scientific-programme/.

If there is something particular you would like to know about feel free to email me and I may be able to help - carolyn@icombo.org.

Phenotypic differences in conjoined twins



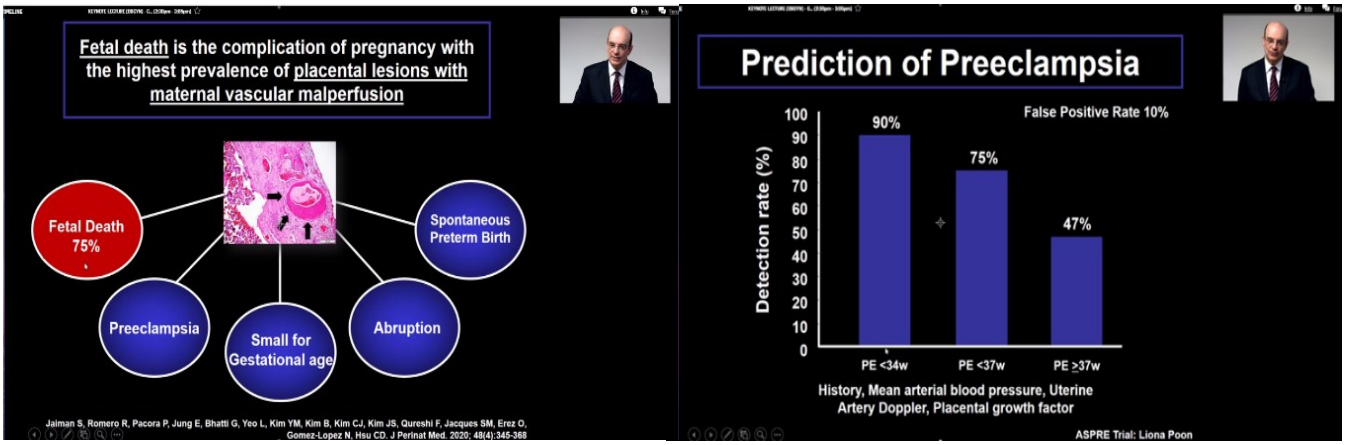
The opening keynote talk of the conference was a fascinating, but at times sad, one from Juliet Butler about the phenotypic differences in conjoined twins. She talked about her time with Masha and Dasha Krivoshlyapova - Russian conjoined twins who whose childhoods were spent in state-run institutions, where they were subjected to horrific "experiments" performed without their consent. So glad things have moved on since then! Juliet is a journalist and wrote the book 'The Less You Know the Sounder You Sleep' which is a fictionalized account of the lives of the twins (https://blogs.sciencemag.org/books/2017/08/15/a-fictionalized-story-of-two-real-sisters-sheds-light-on-the-darker-side-of-human-research/).

It is interesting how so called identical twins can be so different, especially in personality. She has some interesting theories about identical twins and how in many cases one derives their personality from the mother and the other the father. Something we hope to explore more with Juliet and conduct a survey to gather more data so watch this space.

The 5th World Congress on Twin Pregnancy

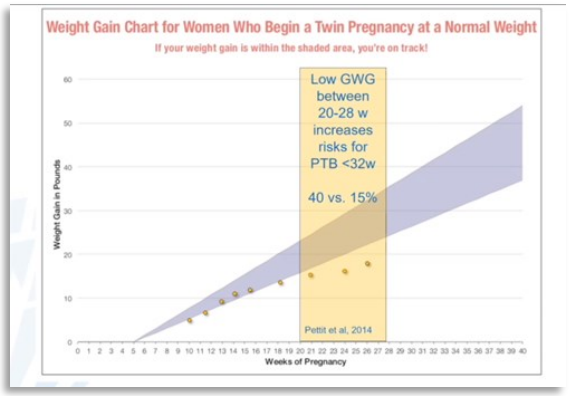
Improving pregnancy outcomes

A further keynote was 'Great Obstetrical Syndromes and their consequences on the mother and the perinate' by Roberto Romero. The highlight of this talk was the progress being made to identify biomarkers for risk factors such as foetal death, preeclampsia and premature birth, all of which are higher in multiple pregnancies. A blood sample taken at 20-23 weeks of pregnancy to determine the maternal plasma angiogenic index-1 (placental growth factor/soluble vascular endothelial growth factor receptor-1) can identify those with placental vascular lesions and therefore at risk. In addition, determining the angiogenic index-1 in maternal blood at 24-28 weeks can identify those at risk of late foetal death and thus allow intervention to reduce that risk. For preeclampsia the combination of mean arterial blood pressure, uterine artery doppler and placental growth factor in the first trimester is highly accurate. Those at high risk can then be given low dose aspirin which has been shown to be highly effective.

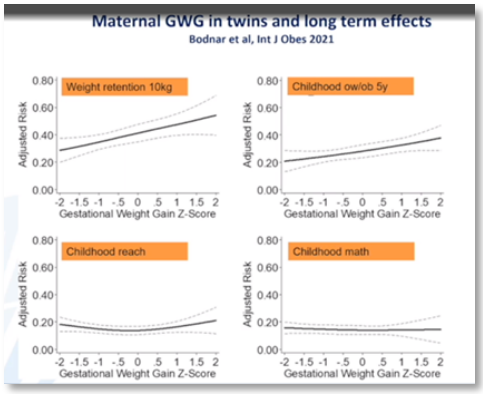


Nutrition in multiple pregnancy

One interesting talk was on nutrition in multiple pregnancy (delivered by Roland Devlieger from Belgium). Did you know ideal weight gain between weeks 20 and 28 is particularly important to reduce the risk of premature birth? There is increasing evidence it is important not to gain too much weight during pregnancy though. Too high a weight gain increases the chance of hypertensive disorders including preeclampsia. There is evidence that low dose aspirin (60-150 mg) should in initiated in all multifetal pregnancies to reduce the risk of preeclampsia. A very recent study presented also indicates high weight gain in pregnancy can increase childhood obesity.



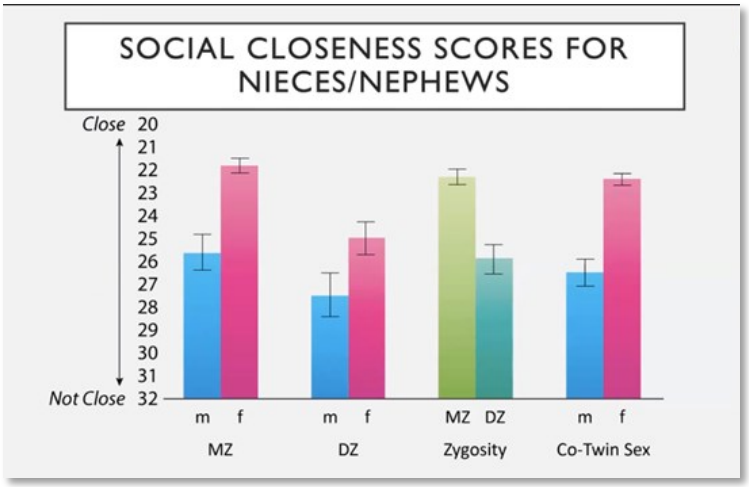
Continued....



To date the evidence is mixed and further studies are needed as some of the numbers are small. However, a couple of key points:
Progesterone at doses used to date is not effective in all twin pregnancies and should only be used if the cervical length is <30 mm. A dose of 400 mg per day appears to be most effective.
Cerclage (stitch) may only be effective in those with a very short cervical length (and needs to be done before 24 weeks) or with those who have a dilated cervix.

Comparative study of social closeness in twin families

Nancy Segal has been studying the closeness of twin aunts and uncles to their nieces and nephews from their twin sibling. Identical twins (MZ) are much closer to their nieces and nephews compared to fraternal twins (DZ). This is probably due to being more closely related genetically and hence greater perceived similarity. Females tend to be closer than males no matter if MZ or DZ. The question then arises to the children of MZ twins feel closer to their aunts and uncles than the children of DZ twins?



The 5th World Congress on Twin Pregnancy

The following additional workshops were documented by Monica Rankin.

How to assess fetal growth in multiple pregnancy? What should be the standard?

Katia Bilardo,
University Medical Centre, Amsterdam
The Netherlands

The labelling of twin fetuses should follow a reliable and consistent strategy and should be documented clearly in the mother's notes. Use as much description as possible, to be as certain as possible. This is important for many reasons, one of which is the perinatal switch phenomenon. Twins that are labelled as "twin A" and "twin B" may have a different birth order, particularly if they are delivered by caesarean section.

⇒ Ultrasound monitoring:

- Uncomplicated dichorionic twin pregnancy
  - Should have 1st trimester
  - Detailed 2nd trimester scan
  - Scan every 4 weeks thereafter.
- Complicated dichorionic twins should be scanned more frequently, depending on the condition and its severity.
- Uncomplicated MC twins should have 1st trimester scan and be scanned every 2 weeks after 16 weeks in order to detect TTTS and TAPS in a timely manner.
- Complicated MC twins should be scanned more frequently, depending on the condition and its severity.

⇒ At each ultrasound, the following should be checked:

- Fetal biometry
- Amniotic fluid volume
- Umbilical artery doppler, from 20 weeks gestation
- Discordance in EFW (estimated fetal weight) should be calculated and documented at each ultrasound from 20 weeks gestation.

Assessing EFW is less accurate in twins than in singleton pregnancies. EFW charts that include a combination of head, abdomen and femur measurements perform best in both singleton and twin pregnancies.

Currently singleton fetal growth charts are often used to monitor fetal growth in twin pregnancies. However there is a reduction in fetal growth in twin compared to singleton pregnancy, particularly in the 3rd trimester. This is particularly marked in MCDA pregnancies. This may suggest that twin charts should be used to document and monitor growth in twin pregnancies.

However, the use of specific twin growth charts is controversial due to the concern that the reduced growth in the 3rd trimester observed in most twin pregnancies might be caused by some degree of placental insufficiency, warranting close observation.

Optimal fetal growth in twins

Professor Gerard Visser
University Medical Centre, Utrech, The Netherlands

There are at least 6-8 different fetal growth charts specifically for twins in use around the world.

The growth in utero is similar to singletons until 30 weeks but thereafter growth rate is likely to be lower. At 1 year of age, twins have similar size as singletons, so there seems to be a catch-up growth. This indicates that lower growth rate during 3rd trimester is not in the genes but in the pathology; and that growth curves of singletons should be used to assess growth.

Studies of optimal fetal growth in singletons have shown that a size/weight around the 90th centile is associated with best perinatal outcome. It has also been shown that for long term survival, the higher the birth weight, the better the outcome. These infants had optimal intrauterine growth, without growth restrictions.

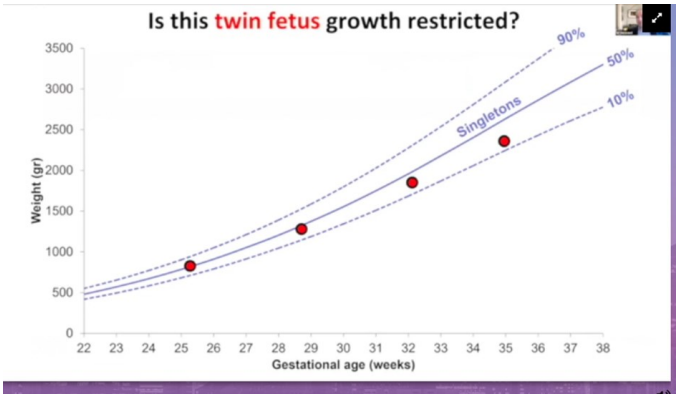
A Dutch study was conducted from 2002 – 2008, with 42,000 twins born between 28 and 42 weeks.
Looking at all twins, it would seem that the optimal birth weight is well under the 90th percentile.
However when zygosity is taken into account –

- For DCDA twins, the optimal weight is 90th centile, just like singletons. This is a good reason to use singleton growth charts. However it doesn't imply that reasons for unfavourable outcomes are similar for singletons and twins.
- Data for MCDA twins is much harder to interpret

The final message from Professor Visser is to use growth charts based on ultrasound measurements and ongoing pregnancies. Using data from pregnancies that had terminated early may provide different results.

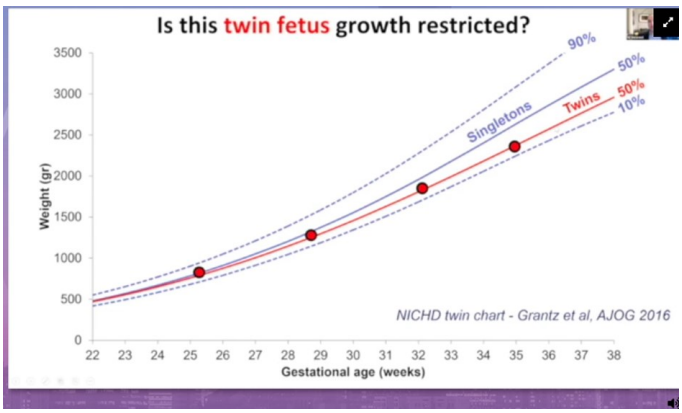
Fetal Growth in Twins
Nir Melamed, MD, MSc
University of Toronto
Waugh Family Chair in Twins Research

On this singleton fetal growth chart, the twin baby is below 50% of that for a singleton, so appears to be growth restricted.



But, looking at the twin fetal growth chart here, the same twin is exactly 50 percentile.

The charts diverge from around 25 weeks



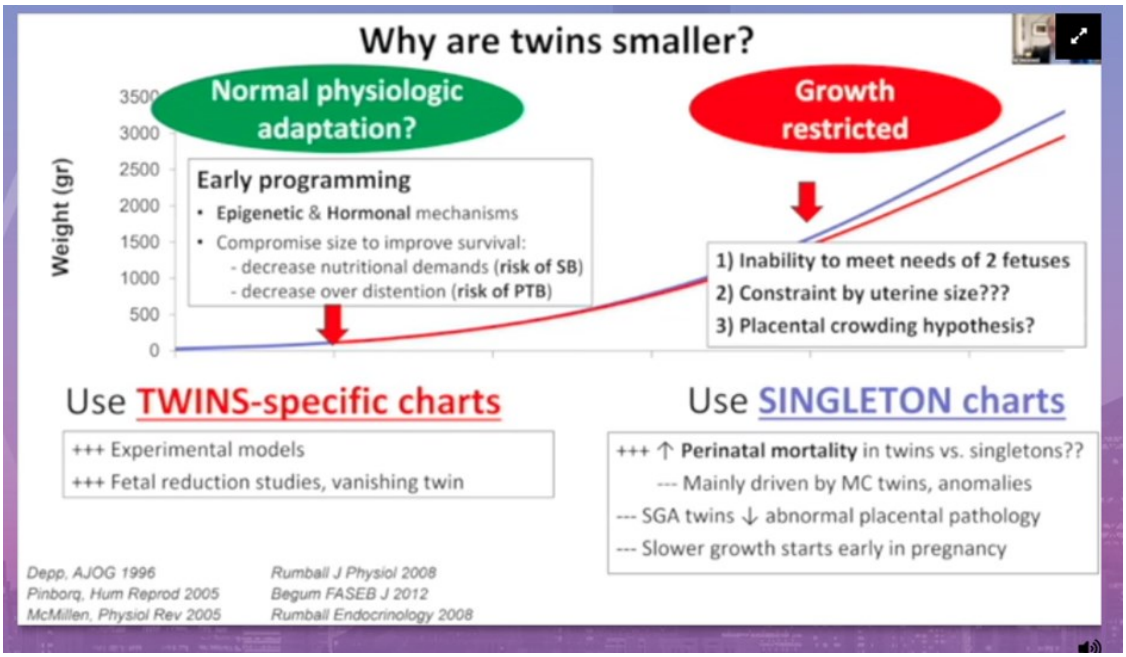
The 5th World Congress on Twin Pregnancy

Using singleton charts show that up to 30-50% of twin babies are SGA (small for gestational age). This leads to implications in resources, interventions, parent anxiety and costs.

So, should singleton charts or twin charts be used to measure fetal growth?

⇒ We need to ask - Why are the twins smaller?
   A. Pathology – use singleton chart
   B. Physiologic adaptation – use twins chart

⇒ Some experts believe that there is a physiological adaption – that twin fetuses compromise their size to improve their survival by decreasing nutritional demands (risk of stillbirth), decrease of distension of uterus (risk of stillbirth and risk of negative mental outcomes).



Which type of chart is more predictive of adverse outcomes related to FGR (fetal growth restriction (stillbirth, neonatal mortality and morbidity)?

The choice of chart has important clinical and research implications.

There is evidence that the use of twin charts:

- Decrease SGA (small for gestational age) from around 30-50% of twins, using singleton charts; down to around 10% when using twin charts
- Gives a more clinically relevant diagnosis of SGA
- It is safe – unlikely to "miss" cases that are at risk of stillbirth

It is reasonable to use twin fetal growth charts, especially if the twins are monitored with regular ultra-sounds.

Recent IUSOG (International Society of Ultrasound in Obstetrics and Gynaecology) and FIGO (International Federation of Gynaecology and Obstetrics) guidelines support the use of twin charts.

Radiofrequency ablation (RFA): indications and techniques

Min CHEN PhD
Guangzhou, PR China

Radiofrequency ablation (RFA) is a procedure that is used to stop the blood flow in an abnormal fetus. This in effect, causes the death of this fetus.

⇒ Indications for the use of RFA –

- Twin reverse arterial perfusion sequence (TRAPS)
- Selective fetal growth restriction
- Twin-to-twin transfusion syndrome (TTTS)
- Twin Anemia-polycythemia sequence (TAPS)
- Discordant structural anomalies
- Monochorionic monoamniotic twin
- Dichorionic twin
- Other reasons

⇒ Twin reverse arterial perfusion sequence (TRAPS)

- RFA was first reported in 2002 for selective reduction in TRAPS
- Very popular for selective reduction in MC twin complications
- The optimal timing of intervention for TRAPS is debated
  - Most wait until at least 16 weeks gestation, until after fusion of amnion and chorion
  - Some perform selective feticide from 12 weeks onwards
  - The data is limited
- A large randomised clinical trial (RCT) is being conducted to investigate the optimal timing of intervention for TRAPS.

⇒ What is the treatment of choice for TTTS?

- Laser ablation, for stage 2 or greater, less than 26 weeks
- Conservative management with close surveillance, for stage 1
- Serial amnioreduction
  - When laser not available
  - More than 26 weeks
- Selective reduction by RFA, when
  - Laser is technically difficult or is not available
  - One of the twins has severe sFGR (selective fetal growth restriction)
  - Discordant malformation
  - Signs suggestive of irreversible damages

⇒ Treatment for TAPS

- Laser
- In utero infusion
- Expectant management
- Selective reduction by RFA
- When other methods have failed
- There is a co-existing abnormality

Continued….

⇒ Discordant structural anomalies

- The choice of selective reduction should be individualised, according to the anomalies
- Potential advantages and disadvantages of the intervention depend on:
  - The type of malformation
  - Its prognosis
  - The acceptability of the malformed fetus to the parents
  - Risk and technical feasibility of the surgical procedure

⇒ Monochorionic Monoamniotic twin pregnancies

- 5% of MC twin pregnancies
- Cord entanglement in MCMA pregnancies is 70%
- A systemic review was conducted of 114 pairs of MCMA twins with cord entanglement
  - The overall mortality was only 11.4% or 26
  - Only 2 cases were directly caused by cord entanglement
- Selective reduction is not the first option solely for cord entanglement

⇒ Dichorionic triplet pregnancies:

- Risks:
  - Lower birthweight
  - Lower gestational age at delivery
  - Higher risk of intrauterine death
  - Selective growth restriction
  - Preterm delivery at less than 32 weeks gestation
- The choice of reduction is further complicated by whether to reduce to a singleton or to a DC or MC twin pregnancy.
- To reduce the independent triplet
  - Simpler procedure but would leave a set of MC twins and the intrinsic risks of MC complications
  - When reducing one of the MC twins and therefore keeping a set of DC twins is preferable, RFA procedure would be required.

Bipolar Cord Occlusion

Prof S Suresh
Chennai, India

Cord occlusion is a common method of selective termination in multiple birth pregnancies.

Absolute indications for selective termination in MC twins

- TTTS
  - Stage 3 / 4 with impending fetal demise
  - TTTS with (severe intrauterine growth retardation) sIUGR
- sIUGR
  - discordancy between twins of greater than 35%
  - a stuck twin
  - type 2 / 3 selective fetal growth retardation
- TRAP Sequencing
  - Volume of TRAP greater than 50% of pump
  - Cardiac compromise
  - Severe polyhydramnios
  - Should all TRAPS be treated???
- Discordant anomaly
  - Hydrops of 1 twin
  - Severe morbidity due to anomaly
  - Impending fetal demise
- Parental choice
  - Higher order MC multiples (triplets or more)
  - All other indicators already listed

All procedures are by informed parent choice.

Bipolar cord occlusion –

- Best performed after 18 weeks
  - At 16 – 17 weeks, 41% experience loss of the healthy baby
  - After 18 weeks, approx. 3% of healthy babies are lost
- Complications
  - Intrauterine fetal death of co-twin post procedure
  - Rupture of membranes
    - Less than 28 weeks, 9%
    - 28 – 34 weeks, 14%
  - Chorioamnionitis
  - Bleeding from puncture site

Continued….

Outcomes for procedure

Results from a study with 118 cases

median gestational age at procedure was 22 weeks (ranged from 6 – 30 weeks)
intrauterine fetal death of cotwin 12% of cases
miscarriage 7% of cases
termination of pregnancy 1% of cases

	Procedure before 19 weeks	Procedure after 19 weeks
Miscarriage rate	45%	3%
Preterm rupture of membranes	38% (13% within 2 wks of procedure)	
Median GA at delivery	34 weeks (24 – 41 weeks)	
Median birth weight	2103gms (480 – 3875 gms)	
Neonatal deaths	9%	Neurological morbidity 2%
Overall survival rate	71%	

Summary

bipolar cord occlusion is an effective technique for selective termination in MC twins should be performed after 18 weeks

Do You Know An Organization That Would Make a Great ICOMBO Partner?

ICOMBO partners like-minded organisations, who work for the betterment of multiple birth families. We invite other organisations to connect with us on our journey.

The TAPS Support Foundation

EFCNI european foundation for the care of newborn infants

The Twin to Twin Transfusion Syndrome Foundation

global alliance for newborn care

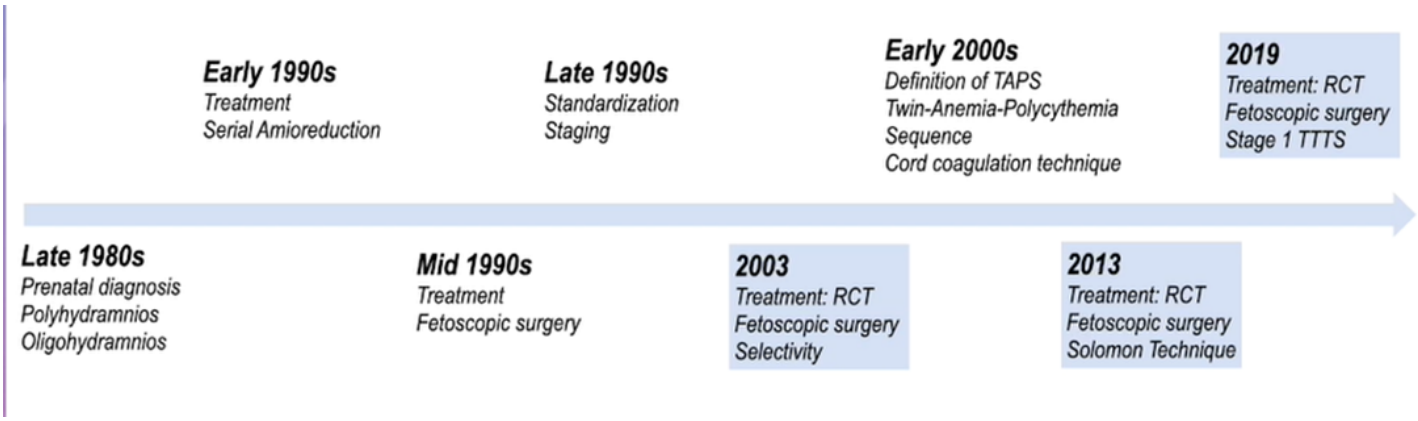
GLANCE

HMBD Human Multiple Births Database

The 5th World Congress on Twin Pregnancy

Update and Overview on Twin-to-Twin Transfusion Syndrome

Yves Ville, France



There is an unresolved issue of preterm premature rupture of the membranes (PPROM) after fetoscopy, it has occurred in up to 20% of cases.

Since the introduction of laser treatment, there have been at least 34 studies done on TTTS cases.

- Survival of both twins has increased from 35% to 65%
- Survival of at least one twin has increased from 70% to 88%
- The mean gestational age at birth is 32 weeks

The question for clinicians is to either:

- Operate immediately stage 1 is diagnosed, or
- Observe and examine each week to see if the fetuses remain stable, and operate if their health deteriorates.

Clinical trials have been conducted and currently the indications are:

- Expectant weekly follow up is a reasonable option for asymptomatic TTT stage 1 with a long cervix.
- 60% of these patients will progress during follow up and will require fetoscopic surgery.
- The outcomes for these patients is similar to those who have surgery immediately.
- In the 40% of patients whose TTTS does not progress, the rate of dual survival is more than 90% and the rate of neurologica

For More Information on TTTS:

The Twin to Twin Transfusion Syndrome Foundation *is an international nonprofit organisation solely dedicated to providing immediate and lifesaving educational, emotional and financial support to families, medical professionals and other caregivers before, during and after a diagnosis of TTTS including TAPS, SIUGR and TRAP.*