

TTTS Times

Official Newsletter of the



Australian Twin To Twin Transfusion Syndrome Support Group

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By becoming a member of the Australian TTTS Support Group, you will assist us in our aim to become a charity. We hope to be able to raise funds in the future, which will be tax deductible to the donor. Our aim is to then use a portion of these funds to produce a brochure with information for parents who are diagnosed with the condition. These brochures will eventually be available at hospitals, obstetricians and other pregnancy related centres. The information to be provided on these brochures has been approved by AMBA and TTTS specialists. We plan to use the rest of our donated funds in our support of parents as well as donating some to TTTS research.

Our membership form is included in this newsletter. If you enjoy our newsletter and would like to help us help other TTTS parents, please feel free to join our support group. Every little bit helps in our quest to promote TTTS and make sure that all parents get as much information as possible.

Thank you,
Vicki and Linda

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Australian Twin To Twin Transfusion Syndrome Support Group

Founded 2002

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Australian Twin To Twin Transfusion Syndrome Support Group aims to:

- Disseminate information about TTTS as a complication affecting multiple pregnancy
- Increase public awareness of TTTS
- Provide information regarding TTTS treatments currently available in Australia
- Provide a general forum for members of the Group
- Co-operate with and participate actively in research projects at local, national and international levels, into all aspects of Twin to Twin Transfusion Syndrome

In pursuit of its objectives, the Group shall be conducted as a non-profit organisation, and shall refrain from sectarian and political activity of any kind.

Services:

- Advice and support for families who are experiencing/have experienced a TTTS pregnancy
- Advice and support for families with intact twins, as well as bereaved, and special needs families
- 6 editions per year of 'TTTS Times', received by all members
- Phone contact on request

Meetings:

- Monthly meeting, held in members' homes
- Coffee Mornings/Afternoons in members' homes or suitable venues

Subscriptions: \$20 per annum (\$15 for AMBA members)

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From the Editor's Desk...

Hi everyone and welcome to edition #2 of *TTTS Times*! We've got a couple of good articles in this edition - some sound information on pregnancy nutrition (vital if you are pregnant and your babies are suffering TTTS - pages 6-7) and Victoria has been kind enough to allow her story to be printed – see pages 8-11.

We've got some exciting happenings coming up with the Support Group - Victoria is lucky (and brave!) enough to be attending the Multiple Pregnancy Conference in Melbourne in February, and we are also looking forward to presenting a TTTS awareness workshop at the AMBA QLD State Seminar in Toowoomba in May. We'll keep you posted on what goes on at these two events.

On the home front, we have had a busy Christmas and New Year - we are in the midst of toilet training our twin boys (not fun!), and their 3rd birthday is coming up - I am going to take the easy way out this year and take them for a trip to McDonald's!

See you next edition.

Linda

To Contribute to TTTS Times...

Stories
Birth Notices
Memorials
Poems etc
...are all welcome

If you have a "must-include" contribution that will be late, please contact the Editor so that ample space will be left available. Some contributions may be edited. Word-processed contributions should be forwarded on diskette or by email. Pictures and photos are welcome as bitmaps or .jpg or hard copies, and photos will be returned. Handwritten submissions are also welcome. Please inform me of the source if it is not your own as permission to reprint is required. Any questions, just call me on (07) 3823 4612 or email linda@twin-twin.org

Any postal submissions to:
Attn: Linda
Australian TTTS Support Group
P.O. Box 1343
Carindale QLD 4152

Happy Birthday to...

Joshua & Caleb Back, who
will be 3 on 26th January.

Australian Multiples Magazine

National Newsletter produced by the A..M.B.A.. Council

Published 5 times per year

HOW MUCH DOES YOUR SUBSCRIPTION COST?

\$7.50 for AMBA members

\$15.00 for non-members

AUD\$20.00 for overseas subscribers

Send CHEQUE PAYABLE TO 'A .M.B.A .'

With your address details to:

AMBA Treasurer

96 Moore Street

HURSTVILLE NSW 2220

Multiple Birth Association Bereavement Support

MBA Bereavement Support Group
(M-BABS)

P.O. Box 1015
Caulfield North VIC 3161

Telephone: (03) 9527 7144
Fax: (03) 9527 2537
E-mail: simone@zmood.net
Web Site: Coming Soon!

The **Multiple Birth Association Bereavement Support Group**

(M-BABS) is a nationwide club affiliated with AMBA providing a means of communication for bereaved multiple birth families and a forum for the sharing of information relating to the tragedy of multiple birth loss.

M-BABS publishes the **Multiple Dreams** newsletter on a quarterly basis.

We are also the Australian agent for the Center for

**For information on the group or to subscribe to the newsletters,
contact the President, Simone Zmood.**

Nutrition During Pregnancy and Breastfeeding

Nicola Fox is an Accredited Practising Dietitian who has a private consultation business in Brisbane. She also travels as far as Maryborough to see patients. Nicola specialises in Nutrition for Pregnancy and Infants, Weight Management, Diabetes, Heart Health and Digestive Disorders. Please feel free to contact Nicola for specific nutrition advice -

Ph: (07) 3311 1860 or 0409 274 125

Nutrition During Pregnancy and Breast Feeding

Good Nutrition is vital during pregnancy and breastfeeding. Choose a wide variety of these foods each day:

- Breads and Cereals
- Fruit and Vegetables
- Meat, legumes, nuts
- Milk/Cheese

If you are following a vegetarian or vegan diet, you may need specialised advice from a Dietitian to ensure your protein, zinc and iron intake is adequate.

Breast milk contains all the nutrition needed for an infant. If your diet is inadequate, your health may suffer, or your volume of milk may decrease.

Iron and Zinc

During pregnancy and breast feeding, iron and zinc needs increase.

Red meat is the best absorbed source of iron in the diet and women who rarely eat meat and have a low energy (calory, kilojoule) intake may be at risk of iron deficiency. It is best to try and consume lean red meat at least 3-4 times per week. Vitamin C enhances iron absorption, so eating tomato or orange juice with your meal will be beneficial.

Zinc deficiency may result in growth retardation and foetal abnormalities. Foods rich in zinc include: oysters (cooked to avoid listeria infection), lean red meat and wheat germ. Milo, Sustagen and some breakfast cereals are fortified with zinc and iron.

Calcium

Pregnancy and breast feeding represent times of increased calcium needs. Good sources of calcium include:

- | | | |
|---------------------------------|---------|-----------------|
| • Milk (low fat, skim or whole) | 1 cup | = 300mg calcium |
| • Yoghurt | 1 tub | = 300mg calcium |
| • Cheese | 25g | = 200mg calcium |
| • Canned sardines with bones | 1/4 cup | = 100mg calcium |
| • Calcium fortified soy milk | 1 cup | = 150mg calcium |

Recommended Daily Intake: Pregnancy = 1100mg; Breast Feeding = 1200mg

eg. 2 glasses of milk, a tub of yoghurt and 2-3 pieces of cheese each day will provide 1100-1200mg calcium.

Folate

All women of childbearing age should increase their daily intake of folate-rich foods, particularly in the month before and the first 3 months of pregnancy to help prevent against their child developing neural tube defects.

A diet based on a wide variety of vegetables (especially green), fruit, legumes, wholegrain breads and cereals is the best way to ensure your folate intake is adequate.

Nutrition During Pregnancy and Breastfeeding (Cont'd)

Aim to eat at least 2 pieces of fruit, 2½ cups of vegetables and 7 serves of breads and cereals every day (1 serve = 1 slice bread, ½ cup rice, pasta, cereal).

During Pregnancy and Breastfeeding (Cont'd)

Aim to eat at least 2 pieces of fruit, 2½ cups of vegetables and 7 serves of breads and cereals every day (1 serve = 1 slice bread, ½ cup rice, pasta, cereal).

Excellent sources of Folate:

- Asparagus
- Bonox
- Bran flakes
- Broccoli
- Brussels Sprouts
- Chick Peas
- Dried Beans (soy, blackeye, red kidney)
- Lentils
- Spinach
- Oranges/Orange juice

What to Avoid during Pregnancy and Breast Feeding

It is best to avoid alcohol during pregnancy and breast feeding. Heavy alcohol intake is associated with Foetal Alcohol Syndrome which includes facial malformation, mental retardation and growth retardation.

Heavy caffeine intake during pregnancy is associated with a slightly higher risk of delivering a low birth weight infant. 1 - 2 cups of instant coffee, tea or cocoa, per day, does not appear to have an adverse effect on the foetus.

Pregnant and Breast Feeding women with a family history of food allergy are advised to avoid peanut products.

Cigarette smoking during pregnancy is associated with pre-term delivery, perinatal mortality and possibly spontaneous abortion. Smoking has the most dramatic effect on infant growth. Smoking should definitely be avoided during pregnancy.

Listeria Infection

Pregnant women are a high risk group for Listeria infection because Listeria infection can be transmitted to the foetus and may cause miscarriage, stillbirth or a very ill new baby. Listeria can be found on the surface of raw unwashed vegetables and in certain processed foods including soft cheese, pate, and some processed meats.

High Risk Foods include commercially prepared:

- pate
- cooked diced chicken
- meat products eg. Ham, processed meats
- soft cheeses eg. Brie, Camembert, feta, ricotta, blue vein
- self serve or packed salads eg. coleslaw, pasta salad
- cold smoked and raw seafood eg. Smoked salmon, oysters, sashimi
- soft serve ice-cream, thickshakes

To make an appointment for more specialised or specific advise regarding nutrition during pregnancy, breast feeding and infant nutrition please contact Nicola Fox (Accredited Practising Dietitian) 07 331 1860 or 0409 274 125

If you have a current medical condition such as Gestational Diabetes, Hypertension, Elevated Cholesterol or Digestive Disorder (Reflux, Coeliac Disease, Lactose Intolerance, Irritable Bowel Syndrome) please don't hesitate to call Nicola Fox (Dietitian) to receive more specific advise.

Permission to reprint in AMBA newsletters granted by author.

Thank You to Sonia Porter (Gold Coast MBA) for organising this article.

Mitchell Adam and Antony Samuel (12 April, 2000)

In June 1999, my husband and I decided it was time to start trying for our fourth child. We already had 3 beautiful sons so we were going to try for a little girl. We read all the books about diet, timing, etc and I had been monitoring my cycle for almost a year. Our third month was a success and on October 18, I tested positive on my home pregnancy kit. I knew in my own mind that I was already pregnant. I was already queasy and the thought of food made me feel awful. On October 27, I went to my GP and had the pregnancy confirmed. I was given a referral to my Obstetrician who had looked after me for my 3 previous pregnancies and was looking forward to seeing him early December. My other pregnancies had been very good and I was one of the fortunate people who found childbirth to be relatively easy so I had been looking forward to this, my last pregnancy.

On December 6, I had my first appointment with my obstetrician. I had been very sick for about the past 10 weeks so he suggested that he do a simple ultrasound scan to check that I was only carrying one baby. Vince and I were very excited to see our little jelly bean moving about on the screen and were also relieved to only see one baby there. As I had been so sick, I was hoping that maybe we had hit the jackpot and conceived a girl. I returned to my OB on January 6, 2000 and all my vitals were very good. I was given a referral to have a proper scan done at around 18 weeks. The first available appointment was on February 1. This suited me as my two eldest returned to school the day before that after the summer holidays.

February 1 came and I was very excited. I had no worries about the baby at that stage and was determined to find out the sex. I lay down on the chair and the technician put the scan on my stomach. All Vince and I could see were two circles. I said to Vince, "That's a head but that's not a bottom, it looks like another head." The technician looked at me and said "Don't you know you are carrying twins?" I burst into tears. I didn't know whether to be happy or overawed. Five children, how scary? The scan continued and I was able to tell that one of the babies was a boy. As the scan progressed we learnt that the twins were identical. Another shock, five boys! I was definitely going to be "queen of the castle" now. After a while, the technician went a bit quiet and said that she would have to get the doctor. She was concerned about the difference in the baby's sizes and also was having difficulty in locating a separating membrane. The doctor came in and told us that it appeared that our beautiful babies were suffering from Twin to Twin Transfusion Syndrome. He explained the condition to us and how serious this was and that the chances of us taking one baby home let alone both was very small. He was able to locate a separating membrane but thought that twin 1 (our larger baby) had four small holes in his heart. He said that they would probably close before birth and that the TTTS was more of a concern. He suggested that we talk to our OB, who I was seeing the next day, and then get treatment at the Centre for Maternal Fetal Medicine at the Mater Mothers Hospital. Vince and I walked out of in a daze. We had gone into the scan with such high hopes and now it looked like we were going to lose our little babies. I clutched my photo of the twins and held it to my heart all afternoon. We told the boys that we were having twins but that they may be very sick. We got on the Internet that evening and looked up TTTS. All the news was bleak and all the treatment was overseas. There was nothing from Australia so we had no idea what our options were. I spent most of the night in tears and was not looking forward to seeing my OB the following day.

February 2 and Vince and I saw my OB. He explained how he had just delivered a pair of twins suffering from TTTS just over a week ago and that they were doing well (these babies happened to be Joshua and Caleb). He said that we should be okay and that he was going to send me to the Mater for all my follow up scans. He gave me the number for the Centre for Maternal Fetal Medicine and I made an appointment for the next day.

February 3 and my first visit to the Centre for Maternal Fetal Medicine. I was introduced to a specialist doctor and was given a thorough ultrasound scan. I felt like I had been through 10 rounds against Mike Tyson as the babies weren't very cooperative. Their sizes were checked and also the output of urine from their bladder. Their brains and hearts were checked and also the blood flow through the cords. We were relieved to find out that there didn't appear to be any structural problems with Twin 1's heart. At last, a little bit of good news. The signs were that Twin 1 was at the upper level of normal and Twin 2 the lower end of the scale. We were told to return in just under 2 weeks for another scan.

Vince and I had already discussed names for the babies. We had already decided on Antony for a boy and now having to think of another name was proving difficult. After much consulting of name books I picked Mitchell Adam for the name of Twin 1. Mitchell means "big" and Adam, I assumed, meant "first" (I later found out it meant "red"). We still couldn't decide on a middle name for Antony but knew that one would come to us when needed.

We returned on February 14 for our next check. I was 20 weeks and 5 days at that stage. They found that there was markedly reduced amniotic fluid around Antony but urine was present in his bladder so that was a good sign. Mitchell's amniotic fluid was at the upper end of the normal range. At that point there was nothing to do but keep an eye on my size and comfort until the next scan in 2 weeks.

Mitchell Adam and Antony Samuel (Cont'd)

On February 28 (22 weeks and 5 days), I had my next appointment. Antony still had decreased amniotic fluid and had a smaller estimated weight than Mitchell (422g compared to 572g) had. It was possible that Antony was suffering IUGR (intra uterine growth retardation) and not TTTS after all.

Next check was on March 20 (25 weeks and 5 days). Nothing much had changed in the condition of the babies. Antony (702g) was still markedly smaller than Mitchell (930g) but there was fluid in his bladder and stomach which were good signs.

I returned on April 3 (27 weeks and 5 days). Mitchell now weighed 1129g (by estimation) and Antony weighed 806g. Things were looking good and I was told that as long as we got to 30 weeks gestation then we should be okay.

The morning of April 5 I attended a morning tea in my honour with all my friends. They presented me with a basket full of baby things which all came in twos. I was apprehensive to accept it as I am always superstitious when it comes to babies.

On April 11 (28 weeks and 6 days), I went for my checkup with my OB. I was feeling better than I had in months and everything seemed to be going well. My blood pressure was up a little bit but not enough to warrant any concern. We discussed the possibility that the babies may be born early and the procedure of having cortisone injections before the birth to help strengthen the babies' lungs. I opted for an elective caesarean, as I didn't want the babies to go through anymore distress than they needed to. I was finally able to relax a little bit and start to enjoy the thought of having identical twins. I hadn't let myself get excited about the prospect before as I was so scared I would lose them.

That evening, I took my eldest to soccer training and my friends commented how well I looked. At about 9:30pm, I started having Braxton Hicks contractions. They were quite strong but eventually stopped. Vince was going to Canberra the next day for work (his last trip until the babies were due) and I told him I felt something wasn't quite right and I wanted him to stay in Brisbane. I went to sleep and then woke up at 12:00am with more Braxton Hicks contractions. They finally stopped at about 1:15am. I was very worried that something was wrong so Vince suggested we go downstairs for a cup of tea. I slowly walked downstairs and as I stood on the tiles, I felt a rush of fluid. Thinking this was my waters, I turned on the light. It was blood! Vince rang 000. I kept reassuring him I was still conscious and lay down on the laundry floor waiting for the ambulance. The ambulance officer assumed both babies had died and was trying to stabilise me before moving me. We went to the hospital with lights flashing and sirens blaring. They estimate that I lost 3 litres of blood. When we arrived at the hospital, I was prepped for a caesarean.

I will never forget when I went into the operating area and had to say goodbye to Vince. I was very scared but I am sure it was worse for him. I was at least asleep while everything happened whereas he had to sit in the waiting room wondering what was happening. Both babies had strong heartbeats when I arrived at the hospital but they were gradually getting slower. Antony started skipping every sixth beat but I was told that hopefully he would be born in time to save him. Our paediatrician turned up for the birth. When I woke up, I had a drip in one arm with the blood transfusion and another drip in the other arm with oxytocin, pethidine and antibiotics. I was told we had lost one baby and the other was clinging to life in the ICN. They wanted to wheel me through to him on my way upstairs as they thought he would soon die. I knew he was strong and told them to take me straight up to my room. They brought Antony (our stillborn) up to stay with us for the day. He was perfectly formed and so beautiful. Vince told me I held him that day although I don't remember. Most of that day is a big blur to me. He stayed with us until late in the afternoon when Vince went home to pick up the boys. We thought seeing me all hooked up would be traumatic enough without them needing to see their lost brother.

The next day, I was taken off my drips and wheeled down to see Mitchell. He was so tiny and very red. This was from all the extra blood Antony had sent into him. He was kept under the ultraviolet lights for about 2 weeks on and off trying to break it all down. On the following night, we held a family service for Antony in the ICN. They closed the nursery for us and we had a priest Bless him. Matt, Ben and Daniel all got to hold him and say their good-byes to him. We took photos with him and also photos of Antony with Mitchell.

We were told that would be important later on when Mitchell grows up. Saying goodbye to Antony that night was the hardest thing I have ever done. The next day we were having an autopsy done and we were never to see him again. The autopsy found that there had been an acute twin to twin transfusion probably causing the placental abruption. His cause of death was ultimately stated as due to the effects of TTTS. At 29 weeks, the babies were a good size (1339g and 1191g) but their lungs, of course, were immature. Mitchell was ventilated for 4 days and then put on CPAP (continuous positive airway pressure). On day 3 he had a brain scan to see if any

damage had been caused by the abruption. It was a very difficult time for us, as we had to prepare ourselves for bad news. Being a Friday they rushed the results to the doctors and it showed a little bit of flaring on one side. We would have to wait a month to have another scan in which time some changes may have occurred due to the damage. The doctors were optimistic that any damage done would be very mild (the follow-up scan showed no change. That we were told was a good sign, so far we have found no problems).

On day 5 we heard him cry and saw him with his eyes open for the first time. The following day, I was discharged and I was able to hold Mitchell for the first time. I found it hard to leave hospital, as when I was admitted, Antony was still alive. As I have now learnt, it was the first of many closures. On day 8, I learnt that Mitchell's weight was now only 1249g. He was being tube fed my milk and started with 1ml every two hours increasing by 1ml every 12 hours if he was tolerating the previous feeds. On day 11 (Easter Saturday), the midwife looking after him detected that he wasn't quite right. She sent for blood tests that showed he had contracted an infection through his central line. It was taken out and a drip put in instead. He was placed back on a ventilator and milk feeds were stopped. It was not an Easter I want to remember, as I was petrified I would lose him. He was back on CPAP 4 days later and then back on milk the following day. Prior to the infection, he was tolerating food really well so they started him back on 6ml every 2 hours. In 3 days his weight jumped 71g. CPAP was also reduced to 6hrs on and 6hrs off. This was a big step and he seemed to bounce back from the infection stronger than before.

We held Antony's funeral on day 17, as by then we were confident Mitchell would be coming home. It was a hard day but I was then able to place all my energy and thoughts onto Mitchell while he needed it. On May 1, I contracted Mastitis, which had hindered me during my other times of breastfeeding. This was the only day I was unable to see Mitchell. I was too sick to even get out of bed so Vince had to do the milk run alone. The following day we learnt that he was tolerating his full feeds for his weight. This was wonderful news, as it now meant that his drip was no longer needed resulting in a smaller chance of contracting an infection. He had also hit the magical 1500g. Within another 2 days, he was taken off CPAP for a trial. They can be moved into Special Care 2 once CPAP is successfully stopped for 48 hours. He was moved to SCN2 but started to tire from breathing by himself, so went back to ICN for CPAP for a few more days. While in SCN2, he was weighed and for the first time, measured. At 32 6/7 weeks, he weighed 1656g and was 45.5cm long with a 29.2cm head. He was so tiny. The day before Mothers Day, I changed my first nappy, which was very exciting.

Two days later, Mitchell was moved back to SCN2. He seemed to improve in leaps and bounds. On May 20, I gave him a kangaroo cuddle and he snuggled up to me and went to sleep. The following day we turned up as he was being taken out of the incubator and put in an open cot. Vince gave him his very first bath and Mitchell found it very relaxing. He then had a feed through his tube and went straight to sleep. He was now receiving his oxygen through a nasal canula. We could now pick him up whenever we wanted. The following day we tried a breastfeed (for the past week he has been learning how to suck on a very small dummy). Each day I was able to breastfeed him one feed and the number of bottles he was given gradually got larger.

After 2 weeks in SCN2, he was promoted to SCN1. All he needed to do before coming home was learn how to suck properly. This took 4 weeks to have him strong enough to take all 7 feeds by bottle or breast. Finally, after 10 weeks of expressing my milk and taking it up to the hospital, we were able to bring our precious bundle home at 39 weeks gestation. I roomed in for a night, which was weird, as it was 10 weeks since giving birth but here I was being woken every 1-½ hours. I worked out that having been mostly bottle fed, he found full breast feeding tiring. When we got home I continued to express some feeds and gave him them in a bottle. Within a week he was fully breast fed. After about 4 weeks I had another bout of mastitis. I decided that was enough. I now had four children to look after and couldn't really afford to be sick. I gradually ceased expressing and put Mitchell on formula. He really packed the weight on then.

When he came home, he was still on 250ml oxygen. I didn't enjoy that experience at all. People would stare at him if we took him out and I was very defensive about that. I preferred it when people asked me about him rather than just gawk at him. After 3 sleep studies at the Respiratory Clinic at the Children's Hospital we were able to reduce his oxygen to nocturnal supply in January, 2001. After one more sleep study in late March he was given the all clear and taken off all supplementary oxygen. I found his first birthday to be a very difficult day. I was so happy that Mitchell was now 1 year old but it was also a day of sadness over my loss of Antony. We also celebrated on June 27 last year. This was the day Mitchell and Antony were due. Last year we were lucky to be able to spend 3 months in San Francisco and that helped me a lot. I was fortunate to get away from everything and spend some time facing up to what had happened to me. For Mitchell's 2nd birthday, I spent the morning upset and that was my time for Antony. Once the clock hit midday, I sparked up and concentrated on Mitchell's birthday for the rest of the day. This worked well and I am going to try and do that on April 12 each year. Mitchell is now almost 33 months old and is growing into a gorgeous little boy. He hasn't had any major delays apart from his speech. He is about 6 months behind and we are attending a speech therapist weekly at the moment. We are also going to start attending a playgroup for children with delays at our local Special Education Development Unit in February. The staff there are very aware of twin traits and believe that Mitchell shows some of them. This, combined with his prematurity, could be a cause of his speech delay. I guess having 3 big brothers doting on him doesn't help either. For a while there he would just point and grunt for what he wanted and hey presto, someone would get it for him. I have just about got him trained to ask for what he wants, even if he just says

"Me". I am hoping that with a bit of hard work, we will have him ready for school in 2006. It seems like so far away but the days travel so fast.

My obstetrician, pediatrician and all the staff at the Mater have done a fantastic job. They not only looked after Mitchell but also helped me recover from such an awful experience. I found the most difficult thing only being able to stay with him for about 2 hours/day. I had 3 other kids to look after and I wanted their lives to continue as smoothly as possible. Mitchell is a very special baby and all his tests have so far come back with no problems. His big brothers dote over him but we will never forget his beautiful twin, Antony. He is always in my thoughts and I know one day we will meet again.

Victoria Sciacca