

# International Vasa Previa Foundation, Inc.

## Executive Committee Meeting Minutes for 7 May 2007

### Executive Committee members present:

- Amy Brown Gaghagen, President
- Mike Krznaric, Vice President
- Victoria Goldstein, Treasurer / PR Committee Chairperson
- Cindy Paris, Secretary / Membership, Nominating Committee Chairperson

### IVPF Committee chairpersons present:

- Daren Samat, Education Committee Co-Chairperson

### Others present:

- None

Meeting began at 5:07pm GMT (11:07am CST)

The minutes of 23 April 2007 were approved for distribution and archival.

The last IVPF monthly members meeting took place 2 May at 1pm CST (7pm GMT). Mike Krznaric hosted. Two IVPF members attended.

The next IVPF monthly members meeting will take place 6 June at 7pm CST (1am GMT). Mike will host.

### **Agenda:**

- Officer Reports
- Treasury Reports
- Membership Committee Report
- Public Relations Committee Report
- Research Committee Report
- Fundraising Committee Report
- Education Committee Report
- Support Committee Report
- Nominating Committee Report
- Old Business
- New Business

### **Officer Reports:**

- President
  - No report given.
- Vice President
  - Mike has established contact with the author of a Letter to the Editor published in response to Globe and Mail coverage of Vasa Previa. The author provided the original version of his Letter to the Editor which was published by the Globe in a severely edited and reduced form. While the authors stated vasa previa incidence rates do not differ much from those used by the IVPF he does dispute our mortality rate estimates. Mike

- will continue communication in an effort to either reach a consensus or at least identify the source(s) of discrepant data. The author's current position is that most Canadian babies do not die from vasa previa, a figure which could be disputed solely on the reports of Canadian vasa previa losses received by the IVPF but will be backed up with related research data.
- Mike has established contact with a representative from the Canadian Perinatal Surveillance System in an effort to understand their position on vasa previa. In a follow up to CTV media coverage, per their request, Mike has submitted a contact list of Canadian parents affected by vasa previa and who indicated they were willing to be interviewed for future media coverage.
  - Secretary
    - Cindy is registering the IVPF as a charity with the Missouri Attorney General at a cost of \$15, but is awaiting a copy of this year's 990 tax return as it is required with the application. This will enable the IVPF to apply for tax-exempt status in Missouri and be included on the Missouri Check A Charity list.
    - Website: The Vasa Previa Foundation in the Netherlands has obtained a new web host. [vasaprevia.com/nl](http://vasaprevia.com/nl) files will be removed from Giacom and the new link [www.vasaprevia.nl](http://www.vasaprevia.nl) will be put on the IVPF website.
    - Renewal period for the domain IVPF.org is up on 6 July. Cindy Paris will renew the domain name.
  - Treasurer
    - A 990 tax return was filed with the IRS in the USA this year.
    - Cindy has spoken with the CHC workplace giving programs and asked them to send donations to the IVPF mailing address to simplify the banking.
    - Victoria Goldstein Macadar will be out of the country from June 8 through July 4. Deposits and banking will be on hold during this time.
    - USA  
Donations and interest: \$800  
Expenses: \$31.50  
Total USA cash on hand: \$41,563.44  
In-kind donations: \$0  
Thank-you notes sent to donors: 0
    - UK (No report given)  
Total cash on hand: £ 604.39

### **Membership:**

- No report given.

### **Public Relations:**

- Since February 2007 there has been widespread media coverage across the globe on vasa previa. In the UK and Canada this has resulted in TV, newspaper and magazine coverage. The effect has been to raise both public and obstetric awareness of vasa previa worldwide. Examples of the work undertaken (including video stream downloads) can be found in the "in the news" section of IVPF web site.
- **UK:** Daren Samat approached the UK Stillbirth and Neonatal Death Society (SANDS) stating that "in the UK 17 babies are born every day either still born or will die before 4 weeks old. That's 6,200 babies per year." He told them he could reduce this figure by over 6% if they help promote VP screening. It is suggested that similar stats in Canada and the USA be researched and that IVPF contact similar organizations in these countries with a similar campaign. Amy will

obtain the figures of stillbirth pre-4 week neonates for the USA and Daren will draft the necessary letters.

- **Australia:** IVPF participating member Professor Ron Benzie has been made the new editor for the Australasian Society of Ultrasound in Medicine in Australia. He wants the IVPF or one of its colleagues to do an opinion piece on vasa previa for their bulletin publication. Yinka Oyelese has agreed to write a piece and has requested guidelines for the article from Professor Benzie. Victoria will follow up with Dr. Oyelese on the progress.
- **USA:**
  - IVPF has been contacted by Parenting Magazine in the USA about possibly doing an article on vasa previa. Two IVPF members have contacted Parenting Magazine as well and the magazine has requested they send in their stories.
  - The American Academy of Family Physicians has published a piece on their website titled "Late Pregnancy Bleeding" which includes well written information on vasa previa. Selective, but not all the most recent medical articles were cited which resulted in a later than recommended delivery date. Mike Krznicar will follow up with the publication. <http://www.aafp.org:80/afp/20070415/1199.html>
- Claudia DiVirgilio published a video about vasa previa and her son Matthew at <http://youtube.com/?v=jXnI0cTGRSw> Well done, Claudia!! Claudia has given permission to 2 IVPF members to use this at upcoming presentations they will be giving on vasa previa.

#### Research:

- No report given.

#### Fundraising:

- **Sophie's Walk:** Registrations have begun coming in for this year's walk. The issue of insurance for some of the larger USA walks is becoming critical. Many locations require coverage and walk routes in these locations cannot be reserved without it. Most locations reserve on a first-come, first-served basis. Victoria submitted an insurance proposal. This particular policy is way too costly. Amy will continue trying for general liability that will cover the walks as well, but at this point it was decided to go with the USATF for insurance for the USA walks requiring it.
- **Community Health Charities (CHC):** This year's Member Council Meeting will be held 13 June at Ameristar Casino in St. Charles, MO. Information has been forwarded to Jeannette Schwartz, Eileen Walters, and Amy Brown Gaghagen. Jeannette states that she may not be able to attend.
- **ClubShop Mail:** <https://www.clubshop.com/cgi-bin/members/MW3253769> The IVPF has been approved. Cindy will get this info up on the website and promote it to the email groups.
- **IVPF Store:** Payment of \$50 has been sent to Jenny Fredrick for 2 dozen Lucas' Angels to be sold in the IVPF store.
  - **Note cards:** It was suggested at IVPF contact artist named Sophie Jordon about designing or letting us use several of her dragonfly pictures as note cards. [http://www.art.com/asp/display\\_artist-asp/\\_/CRID--24549/posters.htm?ui=855D1CE5F9F648A4AE6AE79B9BF39102](http://www.art.com/asp/display_artist-asp/_/CRID--24549/posters.htm?ui=855D1CE5F9F648A4AE6AE79B9BF39102) Additional reminder: Yinka Oyelese has offered us the use of his photographs for note cards. Cindy has organized a number of them into subject groups, ready for this committee to choose some and get them printed.
  - **IVPF Ribbons:** Angel on my shoulder pins are no longer available from Wholesale.dollardays.com Cindy had been looking into this to make IVPF ribbons with and sell in the store and give out at conferences and the walk but the pins were out of stock for a long time and she could not find them anywhere else. Amy is getting samples

on some slightly larger angel on my shoulder pins and some custom made ribbons. Samples have arrived and Amy reports they look great.

- **Auction items (Reminder):** Peter Max donates a piece of his work to charitable organizations for auction. Eduardo Macadar donated a Spanish guitar to the IVPF for auction valued at \$379 USdollars. Eduardo will not be able to list the guitar in his online eBay store. Amy will look into getting an IVPF eBay store.
- **Ben and Jerry's Fundraiser:** One of Elizabeth Paris' friends who works at Ben and Jerry's in St. Louis, MO will be doing a benefit night for the IVPF the end of May. This consists of the IVPF earning a percentage of all the sales that take place on that evening.
- **GoodSearch.com:** Jeannette Schwartz has started some research on this.

#### Education Committee Report:

- **Next meeting:** A new meeting date will need to be fixed as the last was postponed. Daren proposed the following meeting dates: 1 July 2007, 2 Sep 2007 and 4 Nov 2007. He will send out meeting notices to the committee members.
- **Fetal Medicine Foundation of America (FMFA)** <http://fmfaus.meetingpro.info/>
  - OBGYN Ultrasound Update, Chicago, IL 24-26 Aug 2007 IVPF will send materials.
- **The BabyTime Show** International Center, Toronto, Canada, **13-15 April 2007** <http://www.babytime.ca/exhibitor.htm> Mike has remitted funding for this event.
- **15th Annual Symposium New Developments in Prenatal Diagnosis and Medical Genetics May 16, 2007** <http://www.mtsinai.on.ca/seminars/ce/PDMG/> J.J.R. MacLeod Auditorium, Medical Sciences Bldg., 1 King's College Circle, Toronto, Ontario Contact: Tel: 416-586-4800 ext. 2489, [egan@mtsinai.on.ca](mailto:egan@mtsinai.on.ca) This event has been approved. Mike Krznaric is willing and available to staff it. He contacted them and was granted a free booth.
- **American College of Obstetricians and Gynecologists (ACOG) Conference**, San Diego, CA, USA, **May 2007:** <http://www.acog.org/acm/program/welcome.cfm> IVPF will not be attending this event. IVPF is looking into sending literature for delegates. A reminder was made that the deadline for video submission for the next ACOG film festival is usually Oct of the year before.
- **Current Issues in Prenatal Care Annual Conference**, Ottawa, Ontario, Canada, 31 May - 1 June 2007 <http://www.pppeso.on.ca/english/Conference%20Brochure.pdf> Mike Krznaric will check into the booth costs, though he may not be able to attend.
- **6th World Congress in Fetal Medicine 2007**, Cavtat, Croatia [http://www.fetalmedicine.com/wcfm\\_intro.htm](http://www.fetalmedicine.com/wcfm_intro.htm) **17-22 June 2007** IVPF participation at this event is approved. Mike Krznaric and Amy Gaghagen will attend. They have reserved their flights. IVPF will be sharing a booth with Daren and Natalie Samat, who will be attending as the UK Vasa Previa Awareness organization and as IVPF members. Professor Philippe Jeanty is also attending and will deliver a lecture to the Congress on vasa praevia. The Samats and the Partridges have booked and paid for Professor Jeanty's trip. In order to keep IVPF costs to an absolute minimum Daren and Natalie Samat have arranged that there are no costs for a vasa previa booth at this conference. Mike Krznaric and the Samats have funded the cost of their travel expenses themselves. Costs will be the set up of tables, chairs etc. IVPF and UKVP will share these costs.
- **31st British Congress of Obstetrics and Gynaecology (BCOG) Wednesday 04 July - Friday 06 July 2007**, London, England, <http://www.bco2007.co.uk/> BCOG 2007 Secretariat; 4B, 50 Speirs Wharf; Port Dundas; Glasgow G4 9TB; UK [info@bcog2007.co.uk](mailto:info@bcog2007.co.uk) This event is approved pending cost information and volunteers to staff. Carol Prentice has looked into this event. Full registration will cost £450 up until 25 April and £525 after that. Day registration will cost £19. Accompanying persons registration will cost £105 all inclusive of vat. Whilst this is the

sort of event that we should attend, regrettably we do not have the volunteers to cover the event this year.

- **International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) 17th World Congress 7-11 October 2007** <http://www.isuog2007.com/> Florence, Italy. Florence, Italy  
Florence, Italy Amy Brown Gaghagen has confirmed that she will be attending this event. Without other volunteers we are unsure if anyone else will be attending ISUOG 2007. Regrettably Daren Samat is (currently) professionally engaged elsewhere and so cannot attend.
- **Association of Professors in OB/GYN (APGO-CREOG)** <http://www.apgo.org/home/>  
CREOG is part of ACOG. It is the Council on Resident Education in OB/GYN. [http://www.acog.org/departments/dept\\_web.cfm?recno=1](http://www.acog.org/departments/dept_web.cfm?recno=1) **March 2007**, Salt Lake City, UT, USA. A doctor at the ACOG conference suggested IVPF attend. Amy will write to the contact about an application. Cost is \$1,550 (USD). Amy will work on this event for next year.
- **Dar a Luz:** [www.daraluznetwork.com](http://www.daraluznetwork.com) **11-13 April 2008** and has offered us an opportunity to staff a booth there. Cindy has contact Honey about this conference twice and hasn't heard back yet. Amy will phone them up. Daren Samat has checked the web site and it appears IVPF is linked already.
- **International Confederation of Midwives Conference 1 - 5 June 2008**, Glasgow. <http://www.midwives2008.org> ; Royal College of Midwives website at <http://www.rcm.org.uk>  
This is a huge international event. Carol reports that this event would be a chance to influence and inform the profession and make contacts across the world. We have no firm commitment from Carol on this. Amy will write to Carol asking if she will be doing this event. Daren Samat has had some recent contact from Carol Prentice, however is unsure if she will be attending this event.
- **Grand Rounds:** Daren and Natalie propose that when materials are requested for such an event, that the organizer be provided with IVPF printed literature and also be directed to TheFetus.net <http://thefetus.net/listing.php?id=2179> where Professor Jeanty's presentation can be downloaded free of charge (It is currently in 7 versions and languages). It can be downloaded as a self running lecture/presentation, and/or a lecturer controlled presentation. It can also be run without sound if the presenter wants to make a "live" presentation. CME questions have now been prepared for CME accreditation. Daren noted that if we encourage all medical professionals to follow Professor Jeanty's lecture and undertake the CME this will bring about a much needed uniformity of understanding and a uniform clinical approach to the antenatal diagnosis and management of vasa previa for all sonographers, midwives and obstetric professionals. He also states that since its publication online there have been approximately 400 downloads in the 3 weeks since it was made available.
- **IVPF In-Service Presentation Materials:** Pending Amy's review. It was suggested that this presentation be used to replace the current IVPF presentation.
- **Vasa Previa Presentations:**
  - Kristin Edwards will be giving classes on vasa previa at the local medical school where she works. She has obtained permission to use Claudia DiVirgilio's video as part of her presentation, which will also include the new IVPF PowerPoint presentation. Claudia's video will be a fitting way to end the talk.
  - Natasha Donnelly has been asked to speak to a group of midwifery students at the University of Technology Sydney about vasa previa. She would like some IVPF giveaways for this event. Cindy suggested pens, brochures, and bookmarks, as well as the IVPF recommendations and showing the IVPF PowerPoint presentation. Natasha has pens, brochures, and bookmarks left over from the last conference and will use those.
  - Darcie Frederick is doing a report on vasa previa to her college nursing class. Claudia has given her permission to use her video for this presentation. Cindy will offer her the use

- of the new IVPF PowerPoint presentation.
- Daren and Natalie Samat propose that the IVPF PowerPoint not be used for the education of professionals (instead of the Jeanty presentation) because though it is a very good document, it does not carry the weight of a medically qualified professional. They suggest (subject to some editing) that this presentation be used as either a replacement for the current IVPF slideshow and/or as a presentation at a lower level (i.e. at meetings between parents who are experiencing or have experienced vasa previa.) This was agreed.
  - Liselle Towers has requested an IVPF information pack for her doctor. Cindy mailed one out.
  - 50 IVPF brochures have been sent to Susan Dove-Owen, who requested them for distribution in her local community.
  - Philippe Jeanty delivered a key note lecture titled "Vasa Previa: the silent killer of Normal babies" at the May 6th Fetal Medicine Cairo 2007 conference. Daren reports that it was very well received. <http://71.18.85.163/ParallelC.html> Professor Jeanty also attended and delivered the same at a conference in Singapore. He has indicated that wherever possible at conferences that he attends he will attempt to present a lecture on VP.
  - Daren Samat will be attending and speaking at a meeting at New Castle, Australia on 31 May 2007. Topic to be vasa previa. Meeting is being sponsored by Schering Pty. Ltd., under the auspices of the Hunter Post Graduate Medical Institute and the Newcastle Obstetrical and Gynaecological Society.

#### **Support Committee Report:**

- Karen Melnick contacted the IVPF. She has written and published a book titled Your Child's Health & Wellness Record which she states is a great resource for high risk pregnancies and beyond.  
[http://www.healthandwellnessrecord.com/s\\_home.php?osCsid=d946fb774114508cc5c07bf95b48f482](http://www.healthandwellnessrecord.com/s_home.php?osCsid=d946fb774114508cc5c07bf95b48f482) Amy will look into this.

#### **Nominating Committee Report:**

- No report given.

#### **Old Business:**

- **General Liability Insurance:** Jeannette and Amy are contacting insurance companies to get this coverage as soon as possible. They are having problems acquiring this insurance. This is very important for some of the larger walks in the USA. Many locations cannot be reserved (and may not be able to be reserved at a later date) without coverage.
- **Medical Advisory Board:** Amy is drafting invitations. We haven't received any acceptance letters back. Amy will re-contact the doctors. Victoria recommended Dr. Anna Parsons and Susan Guidi, both in Tampa, to be part of the IVPF Medical Advisory Board. Victoria will obtain bios for Dr. Anna Parsons and Susan Guidi.
- **Bar Code System for Conferences:** Daren reports that the prototype may not be ready in two weeks. The reader Phil was sent had to be returned as it was faulty but he hopes to have this problem sorted soon.
- **IVPF Forum:** Tabled for the time being to gauge how the new settings are working out. No new posting emails have been received.

#### **New Business:**

- It was proposed that IVPF pay the costs associated with accrediting Professor Jeanty's presentation on vasa previa. Tabled for further discussion at a later date.

- It was moved and duly seconded that Amy purchase the book “Your Child's Health & Wellness Record” for review. Motion passed unanimously.
- It was moved and duly seconded to approve Jennifer Sheeran and Colette Legein as IVPF participating members. Motion passed unanimously.

Meeting Adjourned at 7:13 pm GMT (1:13 pm CST)

**The next regular IVPF Executive Committee meeting will take place on 21 May 2007 at 11am CST (5pm GMT).**