

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 23 April 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:

- None

Others present:

- None

Meeting began at 5:21pm GMT (11:21am CST)

The minutes of 9 April 2007 were approved for distribution and archival.

The next IVPF monthly members meeting will take place 2 May at 1pm CST (7pm GMT). Amy and Mike will be hosting.

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 Krznaric submitted a 450 word response in a letter to the editor of the Globe and Mail in response to a comment made on their April 5, 2007 article on Vasa Previa. As the word limit is 200 words his response may not go to print but due to the nature of the discussion it cannot be shortened further. As of April 22, 2007 the response did not get published. Mike is considering contacting the author of the comment directly in an attempt to address his response to the article.
- 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. Amy will send her a copy of the 990 tax form.
- The Royal Australian/New Zealand College of Obstetricians and Gynecologists (RANZCOG): A reply has been received and while RANZCOG appreciates the input, they've responded that they feel no guidelines are necessary as they believe that that vasa praevia is adequately covered during undergraduate training and although the condition is rare, Obstetricians & Gynaecologists should be well versed in recognizing and managing the symptoms. It was agreed that Daren Samat meet with the RANZCOG. It has also been suggested that IVPF contact the Australian ultrasound organization ASUM regarding guidelines for diagnosis. Natasha Donnelly will contact the ASUM.
 - A vasaprevia.com email address has been set up for Natasha Donnelly.
 - IVPF Website:
 - The Vasa Previa Foundation in the Netherlands has obtained a new web host. vasaprevia.com/nl files will be removed from Giacom and the new link 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.
 - Amy will contact the CHC and American Express and the AARP workplace giving programs asking them to send donations to the IVPF mailing address to simplify the banking.
 - USA
 Donations and interest: \$72.22 U.S.
 Expenses: \$300
 Total USA cash on hand: \$40,794.94
 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:

- **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.
- **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.
 - Some of the recent UK TV press has been offered to the IVPF for a licensing fee. Cindy has requested a license for the news footage and also requested that the license be donated.
- **Canada:** Today's Parent Pregnancy & Birth in Toronto would like to include a brief item in an upcoming issue about the IVPF a few months down the road and is asking for materials that are distributed to potential donors, and would appreciate having a copy of any materials sent to potential donors. Mike Krznaric had sent them a copy of the most recent IVPF press release and his family's experience with vasa previa. Amy will send Mike similar copy developed and used for the CHC.
- **Parenting Magazine:** IVPF has been contacted by Parenting Magazine in the USA about possibly doing an article on vp.

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.
- **Community Health Charities (CHC):** The next Community Health Charities 4th Wednesday Income Development Conference Call will be at 9 am Wednesday, April 25, 2007. Information has been forwarded to Jeannette Schwartz, Eileen Walters, and Amy Brown Gaghagen.
- **ClubShop Mall:** <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:** Two orders for Lucas' Legacy pins have been received and shipped out. An additional 3 dozen Lucas' Legacy Angels have been received from Jenny Fredrick. One dozen will be used for the free pins and 2 dozen will be used for sales. Cindy will pay Jenny \$50 for the 2 dozen "for sale" pins via PayPal from the store funds.
 - **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 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 several hundred USdollars. Victoria will see if Eduardo can list the guitar in his online 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.

Education Committee Report:

- **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 and Amanda Krznicaric staffed an IVPF booth at the event. They gave out more than 500 IVPF brochures, IVPF recommendations, and all the IVPF pens and wristbands they had. They report that 98% of the people they spoke with were expecting. Several people they spoke with were patients of Dr. Kingdom's and gave Mike and Amanda the impression that Dr. Kingdom is scanning the placental cord connection of all his patients. A number of people had seen Mike and Amanda on TV and thanked them for all they are doing. One person had done quite a bit of research on us and has posted the local news articles on the bulletin board at work as there are a number of expecting women working there. Mike has made a few contacts with local baby retailers and will follow up with them for possible links/articles to the IVPF. Mike is finalizing local funding for this event and will contact the IVPF next week to remit the funds.
- **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 This event has been approved. Mike Krznicaric 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 Krznicaric 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 **17-22 June 2007** IVPF participating at this event is approved. Mike Krznicaric, Daren Samat, and Amy Gaghagen will attend. Mike and Amy have reserved their flights.
- **31st British Congress of Obstetrics and Gynaecology (BCOG) Wednesday 04 July - Friday 06 July 2007**, London, England, <http://www.bcog2007.co.uk/> BCOG 2007 Secretariat; 4B, 50 Speirs Wharf; Port Dundas; Glasgow G4 9TB; UK 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. Daren Samat believes this to be the very sort of conference we should attend. It was noted that we need to nail down IVPF participation in this event very soon.
- **International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) 17th World Congress Sep 2007** <http://www.isuog2007.com/> Florence, Italy. Florence, Italy Daren Samat, Phil Millard and Amy Brown Gaghagen looking into whether in exchange for a bar code system ISUOG will admit IVPF free of charge and as sponsors for this event. Daren reports that Phil will have a prototype ready in about 2 weeks.

- **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 **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 IVPF pending participating member, Honey Rowland, is an accredited leader with Dar a Luz, an international organization who is doing a conference **11-13 April 2008** and has offered us an opportunity to staff a booth there. The organization is in Ohio and stands for Empowered Birth & Beyond and Professional Labor Support. Honey states they may be able to assist you in spreading the word about VP education & support. Cindy has contact Honey about this conference twice and hasn't heard back yet. Amy will phone them up.
- **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.
- **Grand Rounds:** No report submitted.
- **IVPF In-Service Presentation Materials:** Pending Amy's review.
- **Vasa Previa Presentations:** Materials have been sent to Melissa Floor, RN for two presentations she is giving to the labor and delivery staff at her hospital.
- Liselle Towers has requested an IVPF information pack for her doctor. Cindy will mail one out.

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. The book is a recent recipient of the Exceptional Parent Award of Excellence from the Exceptional Parent Magazine. She states that it is an ideal tool for all parents, particularly those experiencing high risk pregnancy and whose children have complex health and developmental issues. Your Child's Health & Wellness Record is a book in which parents record health, wellness and educational details for their child. It is different from other health journals as it is suitable for children who are developing typically and for those who have complex health issues or conditions. It also recognizes the involvement of a wide variety of health practitioners such as medical specialists, occupational therapists, speech and language pathologists, chiropractors, naturopaths, psychologists etc. 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. 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:** Tabled until a formal proposal can be made to this committee. Daren reports that a prototype will be ready in 2 weeks.

- **IVPF Forum:** The Forum settings have been changed, allowing notices to go out when people post. This will greatly enable moderators to more promptly respond to postings. This forum is considered by this committee to be a security risk. Because it is being used, it was decided to continue with the forum for another month and gauge how the new settings are working out. Cindy will contact Karen for her comments on the forum and will make sure that Karen is set up to receive the new posting notifications.

New Business:

- It was moved and duly seconded to approve Allison Paoli as IVPF participating member. Motion passed unanimously.
- It was moved and duly seconded that IVPF continue discussion via an in person meeting with Daren Samat and the RANZCOG regarding establishing guidelines on vasa previa. Motion passed unanimously.

Meeting Adjourned at 6:15 pm GMT (12:15 pm CST)

The next regular IVPF Executive Committee meeting will take place on 7 May 2007 at 11am CST (5pm GMT).