

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 9 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 5:04pm GMT (11:04am CST)

The minutes of 26 March 2007 were approved for distribution and archival.

The last IVPF monthly members meeting took place 4 Apr at 9am CST (3pm GMT). Amy hosted. Four members attended (including the host). The BabyTime show and the new IVPF PowerPoint presentation were discussed.

The next IVPF monthly members meeting will take place on 2 May at 1pm CST (7pm GMT). Mike and Amy 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
 - Dr. Philip F. Hall wrote to the Globe and Mail in response to their April 5, 2007 article on Vasa Previa. His comments appeared presumptuous in nature suggesting that the Globe and Mail story was anecdotal in nature and disputing the vasa previa mortality rate without citing any source. Mike Krznaric submitted a 450 word response in a letter to

the editor. 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.

- Mike Krznaric has been working closely with a family in Canada who contacted the IVPF when they were diagnosed and then un-diagnosed and then re-diagnosed again. The baby was born last week due to bleeding and is doing well. Grandmother, Susan Dove-Owen, extends a big thank you to the IVPF for all the help and support provided during this time. Susan Owen is an IVPF participating member and has requested IVPF wristbands and brochures for an event she is doing. Mike is sending her the materials.
- 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.
 - The Royal Australian/New Zealand College of Obstetricians and Gynecologists (RANZCOG) requested that IVPF file a formal written request that they change their guidelines regarding vasa previa. This has been done and received by RANZCOG who have stated that they will be reviewing our request at their next meeting (next Friday). We will hear back from them the first week of April. Amy has procured a list of OBGYN organizations through out the world and pending the outcome with RANZCOG, IVPF will consider directly requesting the same change in standards from other OBGYN organizations. We are due to hear from RANZCOG in the next week or two.
 - 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.
 - The IVPF forum was hacked taking down the entire IVPF website on 28 March 2007. Cindy implemented a work around getting the site back online within 2 hours. Phil Millard changed the broken code and the website and forum was fully restored on 29 March 2007.
 - Website stats: Website stats show the average number of hits to be doubled since 14 March 2007, up from just under 4,000 per day to 8,000 per day. The most common referrers to the IVPF site are the website of Nathan Elliot paris, google.com, google.co.uk, the "Just What is Vasa Previa" page on Nathan's website, a couple of latinalista archives from August of 2005 (evidently from Sophie's Walk), google.nl, and the Vasa Previa Forum.
- Treasurer
 - IVPF is required to file a 990 tax return for the IRS in the USA this year. Amy has just about finished up the 990. It is due by 17 April.
 - USA
Donations: \$11,125.93
Expenses: \$2,898.75
Total cash on hand: \$41,022.72
In-kind donations: \$0
Thank-you notes sent to donors: 2
 - 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 of 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.
- **UK:** 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:** Mike Krznicaric has made successful contact with the media in Canada resulting in several TV, radio, and newspaper interviews. Pieces continue to be broadcast. Full media links and info available online at <http://IVPF.org/pressroom/inthenews.htm> Mike is continuing to follow up with the print media in Canada and will report on any progress.
- **USA:** IVPF volunteers in the USA continue to follow-up on the press release to the media.
 - IVPF members in the USA have been sending their stories and the recent IVPF press release to their local media outlets. They are reporting some success and we are awaiting news of the articles produced.
- **Parenting Magazine:** IVPF has been contacted by Parenting Magazine in the USA about possibly doing an article on vp.
- **"Letter to Oprah" campaign** has begun with letters requesting all IVPF members and their friends and families to contact Oprah by 31 March asking for a show on vasa previa. Two sample letters have been distributed to members for their friends and families to use. It has been announced by the National Stillbirth Society in the USA that Oprah is officially requesting recent stories of infant loss for an upcoming show they are doing on the topic. This has been verified and stories can be submitted at <https://www.oprah.com/plugger/templates/BeOnTheShow.jhtml?action=respond&plugId=256500001> Victoria suggested we submit a tape as well to <https://www.oprah.com/plugger/templates/BeOnTheShow.jhtml?action=respond&plugId=260500001> International members have been requested to send stories in to Oprah for this campaign due to her media power. It is estimated that at least 500 letters have been sent in. Victoria will begin contacting the producers.
- Julie Austin has been working with a friend in The American Society for Radiologic Technologists (ASRT.org) and reports that due to the articles from the UK, the ASRT will be doing a continuing education unit module on placental abnormalities, including VASA PREVIA. The articles from the UK really impressed upon them the importance of prenatal diagnosis. Kudos to Julie for following this up!
- Jennifer Munson has suggested creating posters of vasa previa victims to use in sending to Oprah and other media outlets. She mentioned that sending her vp miracle's photo into her local media with her story and the press materials had positive results. She will create some samples of this idea and submit. We haven't heard anything new on this yet as Jennifer's computer has been down lately.
- **Petitions:** Two petitions asking that implementation of nationally recognized protocols and standards for the routine screening/antenatal diagnosis and treatment of vasa previa commence immediately. One petition is for UK citizens and ex-patriots and goes directly to 10 Downing Street. This petition is sponsored by the VPUK: <http://petitions.pm.gov.uk/Vasa-Praevia/> The other petition is an international one and can be used anywhere in the world. Cindy suggests that perhaps it should go to obstetrical organizations along with the IVPF request that said organizations include vasa previa in their guidelines. Ideally, UK residents would sign this one in addition to the VPUK sponsored petition. http://vasapraevia.co.uk/ObjBODY_2.htm Emails about the petitions have been sent out to IVPF participating members and the IVPF email group.

Research:

- No report given.

Fundraising:

- **Community Health Charities (CHC):** Jeannette Schwartz attended the CHC meeting held on 28 March in which they gave their regular income development progress report and distributed a summary of last fall's campaign pledges for this year. IVPF will be receiving \$621.07 during 2007 from the CHC/CFC campaign. The first quarterly check for \$113.30 has been received. Carolyn Green reports that this is very good for a first year campaign.
- **Other Workplace Giving Programs:** A matching company donation has been received from American Express, in addition to the donations being received from the American Express Workplace Giving Program.
- **Escrip fundraising program:**
http://www.escrip.com/merchants/identity/schnucks/community_stl.jsp
http://www.escrip.com/merchants/identity/schnucks/stl_coordinators.jsp The IVPF has been approved! The IVPF website has been updated with the information and emails have been sent out to the email groups regarding sign up. It was mentioned that this program has great potential and that follow-up emails should be sent out.
- **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.
- **Google Ad Words Grant:** Amy is applying for it.
- **AIUM Grant:** <http://www.aium.org/eer/procedures.asp> Amy has followed up on this and the application deadline has passed.
- **Lehman Grant:** A check for \$10,000 has been received! It was noted that this grant is for general operating funds and is unrestricted.
- **United Way:** Amy will look into getting the IVPF listed with the United Way in the USA.
- **America's Charities:** Amy will contact them to see if we can get listed with them.
- **IVPF Store:** An order for 6 Lucas' Legacy pins has been received and will be shipped out today or tomorrow.
 - **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 available from Wholesale.dollardays.com
<http://wholesale.dollardays.com/i-166395-n-0/wholesale-angel-on-my-shoulder-pin.html> at a cost of \$79 per case of 100 pins. These pins are small and would be perfect in the middle of a purple awareness ribbon. Cindy had been looking into this to make and sell in the store and give out at conferences and sell at the walk but the pins were out of stock for a long time and could not be found anywhere else. They will be sold in the IVPF store for \$2.50 a piece in Canada, USA, and Latin America; and for \$3.50 a piece in the UK, Australia, NL, etc. Prices include shipping costs. Amy phoned the company about availability and discovered that they are no longer available. A similar but slightly larger pin was found on another website that also makes custom pins. They are sending Amy samples.
- **Auction items (Reminder):** Peter Max donates a piece of his work to charitable organizations

for auction. Eduardo Macadar donated a guitar to the IVPF for auction valued at several hundred USdollars.

- Teresa Spurgeon's mother is doing another small fundraiser with the Eagles in Phoenix to benefit the IVPF.
- Mike Krznic received approval from his scuba club to put on a "Dive for a cause" event and he suggested that this year's cause be the IVPF. Nothing is confirmed since a committee has to agree on the charity but he thinks the chances are good.

Education Committee Report:

- **International Woman's Day 2007 Event: 8 March 2007**
<http://www.scottishwomensconvention.org/> Waiting to hear from Carol about this event.
- **AIUM Annual Convention and Preconvention Program March 15-18, 2007** Marriott Marquis Hotel, New York City, New York, USA
<http://www.aium.org/cmeActivities/events/ann2007/intro.asp> It was decided not to pursue attendance at this event this year due to the budget crunch. IVPF will send materials.
- **Fetal Medicine Foundation of America (FMFA)** <http://fmfaus.meetingpro.info/>
 - (FMFA) 62nd OBGYN Assembly of Southern California: **30-31 March 2007** (FMFA)
 - OBGYN Ultrasound Update, Chicago, IL **24-26 Aug 2007**
- **Perinatal Society of Australia and New Zealand's (PSANZ) 11th Annual Conference** Melbourne, Victoria, Australia **1-7 April 2007**. <http://psanz.eventplanners.com.au/> This event has taken place and appears to have been a big success. Natasha reports that a number of hospitals would like to have Dr. Oyelese come and speak to them on vasa previa. Many who stopped by the IVPF booth are excited about receiving a copy of the Philleppe Jeanty presentation when it becomes available. Natasha reports that the overall level of understanding among the Australian OB community at PSANZ is very high. Almost everyone clinician she spoke to had no problem with the diagnosis and follows the same management plan that IVPF recommends, often doing the delivery even earlier. Many had patients currently in hospital with VP. Everyone who approached the stand was pleasantly surprised that there was a VP Foundation and applauded what we are doing, especially given we are a parent-based group and pretty much self-funded. One doctor did say that the type of people who attend PSANZ would be pretty aware because they have a passion for perinatal health. He gave some great suggestions for other forums for us to target, especially ASUM and the Radiologist College. As these are general sonographers and radiologists (as opposed to OBGYN sonographers) they are the ones who are likely to miss a diagnosis. Tash also found out that ASUM are the ones to prepare the protocols for the 18-20 week scan and that placental cord insertion isn't part of the protocol. She suggests that we approach them requesting they add it in as the next step and volunteers to do this. There is also an annual ASUM conference that she will find out about. There was only one doctor who expressed resistance to IVPF hospitalization recommendation, believing it to be unnecessary in all cases. This was a doctor from California in the USA. A full report and pictures has been submitted already. Tash will collate all her receipts and submit the totals.
- **The BabyTime Show** International Center, Toronto, Canada, **13-15 April 2007**
<http://www.babytime.ca/exhibitor.htm> Mike and Amanda Krznic will staff an IVPF booth at the event and will provide local funding. IVPF is acquiring insurance for the event. If none can be had in the next 2 weeks, Mike will request insurance from the venue itself, which is offering it for \$180. Mike asked for a discount for the insurance and got \$25 off. Mike noted the cost of the insurance went up about \$23, but they are still offering the \$25 off. He has applied for the insurance last week. Also, a local business has offered to help sponsor 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 Course Objectives: The goal of this symposium is to provide useful up-to-date information for physicians and other health professionals on controversial issues in fetal ultrasound findings and new technologies in prenatal diagnosis. It will also provide updates on a variety of recent breakthroughs in the medical genetics field. Mike Krznicar suggested this event and 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 meeting. 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.
- **6th World Congress in Fetal Medicine 2007**, Cavtat, Croatia http://www.fetalmedicine.com/wcfm_intro.htm **17-22 June 2007** Mike has reserved his flights. This conference is an annual event with approx 1,500 OBGYNs from around the World. It is nearly as big as ISUOG and is directly relevant as a target conference. Mike Krznicar (who speaks Croatian) is willing to attend and staff this event as his own expense. IVPF has approved participation in this event. Mike Krznicar and Amy Gaghagen will attend. Daren & Natalie Samat are also planning to attend, at their own expense. Mike and Amy have purchased their air fare already. Mike found a great Bed and Breakfast for him and Amy for only 30 euros per night and plan on sharing a room if possible.
- **National Childbirth Trust (NCT) Conference 2007**, Glasgow, UK: <http://events.nct.org.uk/> **9-10 June 2007** Cost: £295 + VAT for both days, £225 + VAT for one day. Contact: Paul Elbourn Tel: 020 8832 7313, Cell: 07825 235757 Daren has asked Carol if she would be willing to staff an IVPF booth at this event. 600 delegates are expected to attend.
- **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 and there has been a call for extracts by January 2007. 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.
- **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. The deadline for any abstracts is 24 January 2007 (these may also be on video/dvd) and the reduced registration rate ends on 25 April. 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. Accommodation falls into 3 categories and range from £100 per night to £220 per night although rates could no doubt be negotiated. Range of hotels is listed on the Congress website as is the full confirmed programme. 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. Daren Samat, Phil Millard and Amy Brown Gaghagen looking into whether in exchange for a card swipe system ISUOG will admit IVPF free of charge and as sponsors for this event. Amy believes that we need to attend with or without the swipe card system, especially after all the national press from UK and Canada. Daren may be unavailable for this event. Amy and Mike will go, and Cindy is available

if needed.

- **Obstetric Ultrasound: Setting the Standard for 2007**
<http://www.mtsinai.on.ca/seminars/ce/>
<http://www.mtsinai.on.ca/seminars/ce/ObstetricUltrasound/default.htm> **16-Feb-07 to 18-Feb-07** Toronto (Toronto Eaton Centre Marriott), ON CANADA (OB - Maternal Fetal Medicine) Toronto Marriott Downtown, Eaton Centre, 525 Bay Street, Toronto, Ontario, Canada Registration: <http://www.mtsinai.on.ca/seminars/ce/forms/OBUltrasound.htm> It is suggested IVPF send materials for this event unless we can get volunteers to staff a booth. Email with info has been sent to this committee in Dec. This 2-½ day course will address the most current standards in obstetric ultrasound, emphasizing both the early identification of fetal anomalies and the integration of ultrasound findings into a multidisciplinary model of care. This year, a major focus will be on the rapidly evolving role of ultrasound in prenatal screening. Through lectures, workshops, debates, sessions and panel discussions, participants will be brought up to date on current national and international practice standards. This event has passed. It was suggested that we try for this event next year.
- **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.
- **Grand Rounds:** No report submitted.
- **IVPF In-Service Presentation Materials:** Lisa Paine's draft has been reviewed by Cindy Paris, Daren Samat, and Natalie Samat and sent on to Kristy Edwards for completion. Kristy furnished a draft of an excellent PowerPoint presentation suitable for IVPF use. She intends to use this presentation in ongoing classes on vasa previa she will be giving at her local medical school. Edits have been made and IVPF members have been contacted for permission to use their cases in this presentation. Presentation will be submitted to the IVPF Medical Advisory Board before being used in medical school classes, IVPF sponsored grand rounds, mailings, or submitted to websites offering continuing medical education credits (CME). CME paperwork and a medical reference page will need to be drawn up before submitting to CME websites.
- **Vasa Previa Presentations:** Darcie Fredrick is doing a presentation on vasa previa as part of her nursing studies. She has requested information for her report and IVPF materials to hand out to about 24 students who will be seeing the presentation. These have been sent.

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:** We never heard back from Bill Phillippe with bids. Jeannette is following up with other companies to get this coverage as soon as possible. Amy has been contacting insurance agents as well. There is another agent that Jeannette wants to contact. Amy will phone her to discuss.
- **Medical Advisory Board:** In regards to nominating Dr. Phileppe Jeanty for an invitation to MAB, Daren Samat stated that Dr. Jeanty most likely will not accept an invitation to the IVPF MAB and would not appreciate the invitation or any recognition for his work in the field of vasa previa. The Dr. Anna Parsons and Susan Guidi nominations have been tabled pending receipt of their biographical information. Nomination of Dr. Jeanty has been dropped for the time being based on Daren's recommendation to do so, with the stipulation that if he shows any inclination to accept such a position in the future, he will be re-considered for this position. Reminder letters to the doctors previously invited to the MAB will be resent.
- **Card Swipe System for Conferences:** Tabled until a formal proposal can be made to this committee.
- **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 Jessica Daily as IVPF participating member. Motion passed unanimously.
- It was moved and duly seconded to purchase Angel on My Shoulder pins for IVPF ribbons, pending availability at the current vendor, and the IVPF will order as many as necessary to get the best price, but not more than \$1000. Motion passed unanimously.
- It was moved and duly seconded to approve Natasha Donnelly for the IVPF Humanitarian Service Award. Motion passed unanimously.
- It was moved and duly seconded that IVPF attend the 15th Annual Symposium New Developments in Prenatal Diagnosis and Medical Genetics, May 16, 2007 in Toronto, Ontario, CAN. This event is free and Mike will staff. Motion passed unanimously.

Meeting Adjourned at 6:59 pm GMT (12:59 pm CST)

The next regular IVPF Executive Committee meeting will take place on 23 April 2007 at 11am CST (5pm GMT).