

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 12 March 2007

Executive Committee members present:

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

Phil Millard, Vice President was not present.

IVPF Committee chairpersons present:

- None

Others present:

- Mike Krznaric, IVPF participating member

Meeting began at 5:05 pm GMT (11:05 am CST)

The minutes of 12 February 2007 were approved for distribution and archival. Secretary reported that the minutes from 26 February have not been written yet.

The last IVPF monthly members' meeting took place 7 Mar at 7pm CST (1am GMT). Cindy hosted. One member attended. Several items were discussed and are included in the agenda for this meeting.

The next IVPF monthly members meeting will take place 4 Apr at 9am CST (3pm GMT). 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
 - A Certificate of Good Standing has been received from the state of IL (cost \$6). Amy has applied for a Non Profit Corporation Certificate of Authority to do Business in Missouri (cost \$25, Amy paid as in kind donation). Cindy is registering the IVPF as a charity with the Missouri Attorney General at a cost of \$15. This will enable the IVPF to apply for tax-exempt status in Missouri and be included on the Missouri Check A Charity list. These documents are required this year by the Community Health Charities.

- Vice President
 - No report given.
- Secretary
 - No report given.
- Treasurer
 - IVPF is required to file a 990 tax return for the IRS in the USA this year. Amy will complete the form and file.
 - USA (No report given)
Total U.S. cash on hand: \$32,795.56
 - UK (No report given)
Total cash on hand: £ 604.39

Membership:

- There are 127 participating members.
- There are 296 IVPF newsletter group subscribers.
- There are 326 Vasa_Previa email group subscribers.
- This committee continues to moderate and provide maintenance for the IVPF email groups.
- This committee continues to respond to all emails sent to info@vasaprevia.com and initial requests for vasa previa information.

Public Relations:

- Daren Samat made contact with the Sunday Times in London. Reporter interviewed Daren and Natalie Samat and several other members of the IVPF and Medical Advisory Committee for a two part story that ran in UK. Subsequently, the stories were picked up by BBC TV and Radio and other publications as well as a future TV show (like Oprah in the U.S.). Full media links and info available online at <http://IVPF.org/pressroom/inthenews.htm>
- Thanks to the UK stories, the Royal College of Obstetricians and Gynecologists (RCOG) has agreed to change their policy for detecting vp in the UK stating that women with risk factors will be scanned for vasa previa at the 20 week ultrasound!!!!!!
- Running off of the UK success a press release was created to be used worldwide with the media. Release had been sent to Canada and Australia so far for distribution there. In the U.S. press release was sent to more than 100 media outlets and at least 80 of them have been followed up with phone calls. Thanks to Kristen Lewis for follow up phone calls. No results yet, but we are hopeful that someone will help us stop vp deaths in the U.S. once and for all. Aviva Kovacs has volunteered to help with these phone calls as well.
- Letters have been prepared to send to Oprah for both vp angels and survivors families. It was agreed to do this campaign. IVPF members and email subscribers will be asked to write to Oprah en masse before 31 March, members and subscribers sending in their own stories and friends and families sending in the letters composed. It was stressed that we need at least 75-100 letters.
- IVPF has been contacted by Barry Tanner, the Chair of Regulation of The Federation of Antenatal Educators, Suite 228, Office 6, Slington House, Rankine Road, Basingstoke. RG24 8PH Tel: 0870 803 1728 Email info@fedant.org regarding a weblink on their website for the IVPF. <http://www.FENDANT.org> Cindy will follow up on this.
- An article called "Understanding Vasa Previa" was found on <http://www.amazingpregnancy.com/pregnancy-articles/473.html> Cindy followed up with the author correcting a couple of bits of information published there about vasa previa.

- Kristen Lewis contacted the editor of the Carolina Parent who is willing to do a story about her miracle baby Chase and several other Carolina IVPF parents who are willing to be interviewed. Story will be printed in July. Kristen is also working with another reporter in Cincinnati who may do the same. She has been encouraging subscribers of the Vasa_Previa email list for contacts.

Research:

- No report given.

Fundraising:

- **Leman Grant:** IVPF has learned that this grant request has been approved for \$10,000. Additionally, Lehman usually gives grants in 5 year blocks of time which means that this will probably amount to \$10,000 per year for the next 5 years.
- **Chiron Grant:** pending
- **Community Health Charities (CHC):** Application for 2007 has been filed. Several additional forms were required and have been sent in. A meeting has been scheduled by the CHC for 28 March in which they will give their regular income development progress report and distribute a summary of last year's campaign pledges and ad specifications for this year's materials. Jeannette will attend the meeting. **St. Louis Gateway Area Combined Federal Campaign (CFC):** IVPF has received a list of 2 employees who are donating to the IVPF through this federal employee Workplace Giving Program. There may be more than 2 employees giving to the IVPF through this program, but only 2 gave permission for CFC to share their contact information with us.
- **Other Workplace Giving Programs:** A check has been received from the AARP workplace giving program that an IVPF member participates in.
- **The St. Louis Women's Fund** <http://www.soswomensfund.org/> Pending.
- **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> Victoria is applying for this for the grand rounds program.
- **Victoria's Pewter:** Victoria had pewter sales this month which will net the IVPF \$80. She has about 20 pieces left and will put them up for sale on eBay.
- **America's Charities:** Amy will contact them to see if we can get listed with them.

Education Committee Report:

- **Fetal Medicine Center in Dubai** is holding a conference **2-3 March 2006**. Dr. A. Pour Mirza has invited the IVPF to attend at no cost. Unfortunately, there was just not enough time to attend this event as the invitation came in on 14 February.
- **International Woman's Day 2007 Event: 8 March 2007** The Scottish Women's Convention (SWC) has contacted Carol Prentice about IVPF participation in this event. The SWC provides opportunities for women to engage in focused debate about specific issues of concern and to influence policy decisions in Scotland. This event has been approved pending cost information.

<http://www.scottishwomensconvention.org/> We have not yet heard from Carol if she did this event.

- **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). Victoria asked for discount, but never heard back. She will contact them again. It was suggested that Bryce and Miriam Gerritsen be asked to help staff or even help fund this event with VPF of Utah dollars. Due to the late date and lack of progress, it was decided to try for this event again next year.
- **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 did not send materials as planned. It was suggested we send materials to the delegates anyway and mentioned that we need more volunteers to handle the work load.
- **Fetal Medicine Foundation of America (FMFA)** <http://fmfaus.meetingpro.info/>
 - (FMFA) 62nd OBGYN Assembly of Southern California: **30-31 March 2007**
IVPF will send materials.
 - (FMFA) OBGYN Ultrasound Update, Chicago, IL **24-26 Aug 2007**
IVPF will send materials.
- **The Royal Woman's Hospital Health Conference 29-31 March 2007** Crowne Conference Centre, Melbourne, Australia <http://thewomens.org.au> Discounted attendance fees for PSANZ delegates. It was decided that this was too close in to organize. The Royal Women's Hospital Health Conference will feature internationally renowned clinicians and researchers, presenting clinical, scientific and social perspectives and the latest advances in women's and newborn health.
- **Perinatal Society of Australia and New Zealand's (PSANZ) 11th Annual Conference** taking place in Melbourne, Victoria, Australia **1-7 April 2007**. <http://psanz.eventplanners.com.au/> This event is approved, application has been made, and the event paid for. We have 6 local volunteers for this event already, possibly 7. Natasha Donnelly, who suggested the event, is heading it up. Expenses for Natasha's airfare and a rental car has been remitted to her. IVPF materials were shipped to Natasha's sister who lives in Melbourne to avoid her having to bring them on the plane. A table and chairs will need to be rented for the event. IVPF materials in the UK (stands and posters, etc) have been sent to Natasha. They expect about 600-700 attendees at this event. Copies of the RCOG statement about changing their guidelines for vasa previa testing has been printed and included in the materials to be handed out.
- **The BabyTime Show** International Center, Toronto, Canada, **13-15 April 2007** <http://www.babytime.ca/exhibitor.htm> Mike and Amanda Krznic are seriously considering attending this local baby show and staffing an IVPF booth at the event. The BabyTime Show has a "Resource Section" available to non-profit organizations. It is Mike's intention to hand out the IVPF brochure. Mike followed up on this and discovered none of the \$400 non-profit booths are available any longer but \$850 non-profit booths are. Mike has acquired local funding for this event but needs insurance as required by the event venue. Jeannette is working on acquiring a general liability policy. Mike will ask Claudia DiVirgilio to see whether she'd like to attend as well. It was decided to go ahead and apply for this conference and continue to work on obtaining insurance coverage.
- **6th World Congress in Fetal Medicine 2007**, Cavtat, Croatia http://www.fetalmedicine.com/wcfm_intro.htm **17-22 June 2007** 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. Daren & Natalie will attend. Mike Krznic (who speaks Croatian) is willing to attend and staff this event as his own expense. IVPF has decided to go ahead with this event.

- **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.
- **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.
- **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 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.
- **International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) 17th World Congress**, Florence, Italy **Sep 2007** <http://www.isuog2007.com/> Amy will attend this event. 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.
- **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. Mike Krznic will follow up and help with this event 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 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. The event is being

held in Ohio (we think) Cindy has written Dar a Luz twice about this and hasn't yet heard back. The location of the conference is unknown but it is thought to be Ohio as that is the home office of Dar a Luz. Amy and Cindy will be able to attend this event if it is being held in Ohio.

- **Grand Rounds:** A hospital in Massachusetts, USA has requested IVPF sponsor a presentation at their facility. The information has been forwarded on to Jenna Steckler who will follow up.
- **IVPF In-Service Presentation Materials:** Lisa Paine has sent Cindy a preliminary presentation draft. Cindy will review and follow up on this this week.
- **Website stories:** Several stories have been added to the IVPF website.
- **The Midwifery Study Group** in Vancouver, Canada will have a section on vasa previa during their May class. Information can be found at <http://www.glorialemay.com/events.htm> Cindy has written to the class organizer with additional information about vasa previa.

Support Committee Report:

- Keri Vester forwarded an important TV piece about a local hospital that provides professional photography resources for parents with critically ill newborns: <http://www.king5.com/sharedcontent/VideoPlayer/showVideo.php?vidId=122468> Cindy forwarded this to the support committee in the hopes that IVPF members could contact their local hospitals requesting similar resources be used for parents with critically ill children. It is hoped that IVPF members will help promote the idea the website promotes (in-hospital referral program for professional photographers for critically ill babies). It was suggested that IVPF suggest to IVPF members to contact the maternity wards of their local hospitals and ask them to utilize this website information to start a similar program in their hospitals.

Nominating Committee Report:

- No report given.

Old Business:

- **General Liability Insurance:** We never heard back from Bill Phillippe with a bid. Jeannette will follow up with another company regarding general liability coverage. Jeannette is expediting this due to the need for insurance for the Canadian event next month. Amy will also start working on it as well.
- **Medical Advisory Board:** We haven't received any acceptance letters back. Amy will re-contact the doctors.
- **Card Swipe System for Conferences:** Tabled until a formal proposal can be made to this committee.
- **IVPF Forum:** Deletion of this forum has been tabled pending forum statistics and archival.

New Business:

- It was moved and seconded to approve IVPF attendance at The BabyTime Conference.. Motion passed unanimously. Amy will file the application for the event.
- It was moved and duly seconded to approve IVPF attendance at the 6th World Congress in Fetal Medicine. Motion passed unanimously.

Meeting Adjourned at 6:24 pm GMT (12:24 pm CST)

The next regular IVPF Executive Committee meeting will take place on Monday 26 March 2007 at 5:00 pm GMT (11:00 am CST, 12:00 noon EST).