

# International Vasa Previa Foundation, Inc.

## Executive Committee Meeting Minutes for 26 March 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 5:01 pm GMT (11:01 am CST)

The minutes of 26 February and 12 March 2007 were approved for distribution and archival.

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
  - We are sad to announce that Phil Millard has resigned the position of Vice President. But we are pleased to announce that Mike Krznaric has agreed to take on the position of Vice President.
  - IVPF is now incorporated as a foreign corporation in the state of Missouri and has a certificate of Good Standing from that state. A corporate report will have to be filed with the state once each year.
  - 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.

- Vice President
  - No report given.
- Secretary
  - IVPF email addresses have been set up for Daren Samat, Natalie Samat, and Mike Krznaric.
  - Mike Krznaric has been added to the [info@vasaprevia.com](mailto:info@vasaprevia.com) forwarding list.
  - The IVPF event calendar at <http://groups.yahoo.com/group/IVPF/cal/> has been updated with this year's events.
  - 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 had been 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 Gaghagen has procured a list of OBGYN organizations through out the world and pending the outcome with RANZCOG, will consider requesting the same from other OBGYN organizations.
  - Natasha Donnelly has checked the spina bifida rates in Australia and comes up with figures far different than in the USA: 2:1000 births. So, we won't be using the spina bifida statement in Australia. USA figures have been double checked with the Centers for Disease and Control (CDC) and stand as they are. VP occurs twice as often in the USA as spina bifida does
- 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.
  - 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 132 participating members, and six pending members.
- There are 301 IVPF newsletter group subscribers.
- There are 333 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](mailto:info@vasaprevia.com) and initial requests for vasa previa information.

### **Public Relations:**

- Mike Krznaric has made successful contact with the media in Canada resulting in several TV, radio, and newspaper interviews. Full media links and info available online at <http://IVPF.org/pressroom/inthenews.htm> Yinka Oyelese MD was interviewed for these pieces. Dr. John Kingdom at Mt. Sinai Hospital was also interviewed for one of the pieces and stated that diagnosing vasa previa only takes a couple of minutes, that the equipment and training is already in place to do this, and that the only reason Canada doesn't routinely scan women with risk factors for vasa previa is that it is not part of the Society of Obstetricians and Gynaecologists in Canada (SOGC) standard of care to do so. He even demonstrated on TV how fast and simple it is to do. Mike is continuing to follow up with the print media in Canada and will report on any progress.

- Several Canadian citizens have contacted the IVPF offering interviews and help with the Canadian media.
- IVPF volunteers in the USA continue to follow-up on the press release to the media.
- **"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>
- 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.
- **Parenting Magazine** in the USA contacted the IVPF about possibly doing an article on vp. Victoria Goldstein is handling this.
- The UK press pieces continue to be picked up and distributed by other newspapers in the UK. Full media links and info available online at <http://IVPF.org/pressroom/inthenews.htm>
- **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](http://vasapraevia.co.uk/ObjBODY_2.htm) Emails about the petitions have been sent out to IVPF participating members and the IVPF email groups.
- IVPF members in the USA have been sending their stories and the recent IVPF press release to their local media outlets.

#### Research:

- No report given.

#### Fundraising:

- **Lehman Grant:** pending
- **Community Health Charities (CHC):** Community Health Charities (CHC): 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 fall's campaign pledges for this year. Jeannette will attend the meeting. CHC checks have not come in yet. Cindy spoke with Carolyn Green recently who informed her that checks from last fall's giving campaign should start trickling in now and will continue to come in through this time next year. Some checks may be monthly, some quarterly depending on how the individual companies work this program.
- **Other Workplace Giving Programs:** Two checks have been received from the American Express workplace giving program that an IVPF member participates in and also from the AARP, another workplace giving program that an IVPF member participates in. Carolyn

suggested that IVPF solicit members asking them to request that their employers include the IVPF in the Workplace Giving Programs. If there is no program in place, CHC will be happy to contact them and set one up. Carolyn mentioned that employers usually pay more attention to employee requests of this nature than they do to her. This last item really needs to be implemented as the workplace donations we are getting outside of CHC are paying quite well. If it was implemented throughout the USA it would be quite a considerable amount of income. It was mentioned that it is a LOT easier for our members to have their employers add us to the workplace giving programs than it is to go with CHC. A whole lot less work on our part and no paperwork or extra work on our part.

- **United Way:** Amy will look into getting the IVPF listed with the United Way in the USA.
- **The St. Louis Women's Fund** <http://www.soswomensfund.org/> Amy has followed up on this and the application time has expired.
- **Escrip fundraising program:**  
[http://www.escrip.com/merchants/identity/schnucks/community\\_stl.jsp](http://www.escrip.com/merchants/identity/schnucks/community_stl.jsp)  
[http://www.escrip.com/merchants/identity/schnucks/stl\\_coordinators.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.
- **America's Charities:** Amy will contact them to see if we can get listed with them.
- **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.
- **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.
- It was mentioned that IVPF needs volunteers to help implement the last 2 items here.

#### 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/> 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 shipped to Natasha. 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. It was mentioned that this event appears to be money VERY well spent. It is expensive, but we are making good inroads in Australia already, just being signed up!

- **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.
- **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) 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 Krznic suggested this event and is willing 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](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. Daren & Natalie will attend. Mike Krznic (who speaks Croatian) is willing to attend and staff this event as his own expense. IVPF attendance at this event is pending. IVPF has approved participation in this event. Mike Krznic and Amy Gaghagen will attend.
- **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 abstracts 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.
- **31st British Congress of Obstetrics and Gynaecology (BCOG) Wednesday 04 July - Friday 06 July 2007**, London, England, <http://www.bcoc2007.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. 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.

- **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.
- **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](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) 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 has sent Cindy a preliminary presentation draft. Cindy reviewed the draft and sent it on to Kristy Edwards who put it in powerpoint format and sent it back to Cindy for edits.
- **Website Stories:** Three stories been added to the IVPF website.
- **Website Links:** Barry Tanner of the Federation of Anetenatal Educators in the UK has contacted the IVPF and reported that they have included an IVPF website link on his website.

#### Support Committee Report:

- No report given.

#### 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 and is waiting to hear from one of them today.

- **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. Anna Parsons is one of the professors at the FMFA meetings we attend in Ft. Lauderdale and very well respected. Susan is a sonographer who has her own practice and is one of our staunchest supporters. Cindy recommended Dr. Phillepe Jeanty.
- **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 duly seconded to approve Sarah Nelson, Lacy Rozo, Kristy Edwards, Louise Rawlins, Susan Dove-Owen, and Kristin Hardy as IVPF participating members. Motion passed unanimously.

Meeting Adjourned at 6:10 pm GMT (12:10 pm CST)

**The next regular IVPF Executive Committee meeting will take place on 9 April 2007 at 11am CST (5pm GMT).**