

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 21 May 2007

Executive Committee members present:

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

Amy Brown Gagghagen, President was on vacation.

IVPF Committee chairpersons present:

- None

Others present:

- None

Meeting began at 5:06pm GMT (11:06am CST)

The minutes of 7 May 2007 were approved for distribution and archival with 2 changes.

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
 - IVPF has been in contact with a family who was diagnosed with vasa previa and who recently relocated to Canada and will not qualify for medical coverage until a couple of months after the baby is born. Paying these medical bills, which could be as high as \$15,000CAD, will be a terrible hardship for this family. Mike has been in communication with the family and informed them that the IVPF itself is unable to help financially but that we will try to support her with in other ways. It was suggested that IVPF hold a special fundraiser specifically to help this family. It was agreed to auction the donated Spanish guitar on eBay for this cause as well, and possibly obtain other

items to auction for this particular cause. A special PayPal link will be created for this fundraiser and emails sent out to the membership asking them to participate. Victoria will send details on the guitar so Amy can list it on eBay with a reserve of \$299USD. Hospitalization has been verified. A copy of the medical bill and a statement from the hospital will be requested before making payment of any funds raised. Mike will notify the family of these activities.

- 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 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.
 - A disclaimer has been written and posted on site by link. Eventually the links to this and the privacy policy will be included on all pages of the website. Right now it is only on the pages in the root. A shortened version of the disclaimer and links to it and the privacy policy has been included in the footers of the IVPF and Vasa_Previa email groups.
 - Two pages on the website have been changed:
<http://IVPF.org/protocol/protocol.htm> and
<http://IVPF.org/Objectives/objectives.htm>
 - It was mentioned that the current PayPal link launches in the IVPF website frame. Cindy will recode the link to launch in a new window.
- Treasurer
 - 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
No report given
Total USA cash on hand: \$41,563.44
 - UK
No report given
Total cash on hand: £ 604.39

Membership:

- No report given.

Public Relations:

- No report given.

Research:

- No report given.

Fundraising:

- **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 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:**
 - **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. Jenny Fredrick found some more angels online at http://cgi.ebay.com/50-Silver-Angel-Pins-Jewelry-Religious_W0QQitemZ160114600361QQihZ006QQcategoryZ15139QQrdZ1QQcmdZViewItem
- **Auction items (Reminder):**
 - It was suggested that we auction off some of Yinka's photos for the special fundraiser to aid the family in need. Victoria will look into this.
 - 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.
 - Intellibed: Intellibed.com in St. Louis phoned inquiring about opportunities to donate items to the IVPF for auctions. He'd gotten our name from Community Health Charities. Since CHC doesn't do auctions they gave them a list of the charities that CHC works with. Intellibed has stores in several states and sells their products online, so having an item from them to auction off to members and on eBay would be a good thing. They also indicated that they might donate an item for the local walk. We need to fax them IVPF information requesting a donation.
- **Ben and Jerry's Fundraiser:** The end of May 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. This consists of the IVPF earning a percentage of all the sales that take place on that evening. We don't have a date yet.
- **GoodSearch.com:** Jeannette Schwartz has started some research on this.

Education Committee Report:

- Because she feels her job as acting chair person is done now, thanks to the excellent work and leadership of Daren and Natalie Samat, Cindy Paris has resigned as a general member of the Education Committee. She will keep up with finalizing the IVPF PowerPoint though.
- **Fetal Medicine Foundation of America (FMFA)** <http://fmfaus.meetingpro.info/>
 - OBGYN Ultrasound Update, Chicago, IL 24-26 Aug 2007 IVPF will send materials.
- **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 Mike attended this event and staffed the IVPF booth. The event was attended by 80-120 healthcare professionals of whom <10% were OB's (his best guess and is not based on any statistics). Two OB's from Mt. Sinai indicated that they already scan for central umbilical cord insertion and gave the impression that it is standard practice at their hospital. Also they all indicated that they already have the ACOG article. He spoke to 5-10 u/s techs a number of which showed interest in the photos/videos in Jeanty's presentation. He directed them to where they can download the presentation. Based on the conversation with the u/s techs combined with what he was told by an ultrasound machine manufacturer present at the conference, Mike is quite confident that color Doppler capabilities are available in 99%+ (if not 100%) of health care facilities in Canada. A number of health care professionals who work in pathology said that they see vasa previa often. In total he gave out about 30-40 packages of IVPF materials.

- **Current Issues in Prenatal Care Annual Conference**, Ottawa, Ontario, Canada, 31 May - 1 June 2007 <http://www.pppeso.on.ca/english/Conference%20Brochure.pdf> IVPF will be sending materials.
- **6th World Congress in Fetal Medicine 2007**, Cavtat, Croatia http://www.fetalmedicine.com/wcfm_intro.htm **17-22 June 2007** IVPF participation at this event is approved. Mike Krznicaric and Amy Gaghagen will attend. They have reserved their flights. Daren and Natalie Samat will be attending as the UK Vasa Praevia Awareness Group. Professor Philippe Jeanty is also attending and will deliver a lecture to the congress on vasa previa. 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 Krznicaric and the Samats have funded the cost of their travel expenses themselves.
- **International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) 17th World Congress 7-11 October 2007** <http://www.isuog2007.com/> 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. Daren Samat will not be able to attend.
- **The Perinatal Society of Australia and New Zealand 12th Annual Congress (PSANZ): 20 - 23 April 2008**, Event Coordinator, Sarah Smith, on +61 07 3858 5578 or via email psanz08@eventplanners.com.au Gold Coast Convention and Exhibition Centre, Queensland. IVPF has been invited to participate in and sponsor this event.
- **Grand Rounds:** No report submitted.
- **Vasa Previa Presentations:**
 - Kristin Edwards gave a presentation for the medical students at Oklahoma State on April 17th and has one scheduled for May 15th and May 21st for the physician assistant students at OU.
 - Phillipe Jeanty's vasa previa presentation is available online at <http://www.thefetus.net/index.php> Cindy will put a link to this presentation on the IVPF website.
- Victoria will ship bookmarks and pens she has been storing to Cindy and Amy who need them for mailings and conferences.

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. Amy will look into this.

http://www.healthandwellnessrecord.com/s_home.php?osCsid=d946fb774114508cc5c07bf95b48f482

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. The current plan is to go ahead with USATF routes for USA cities requiring insurance.
- **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.
- **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 and duly seconded that IVPF launch a fundraising effort to assist a Canadian vasa previa family with covering their hospital costs related to management of their current vasa previa pregnancy. The fundraising efforts will include a call to the IVPF membership for financial donations to be remitted via a new Paypal link, a call for donation of auction items from the IVPF membership (and other companies), and an auction of a guitar donated to IVPF. Motion passed unanimously.

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

The next regular IVPF Executive Committee meeting will take place on 4 June 2007 at 11am CST (5pm GMT).