

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 7 August 2006

Executive Committee members present:

- Amy Brown Gaghagen, President
- Phil Millard, Vice President
- Cindy Paris, Secretary / Membership, Nominating Committee Chairperson

Victoria Goldstein, Treasurer / PR Committee Chairperson was not present due to being on vacation.

IVPF Committee chairpersons present:

- None

Others present:

- None

Meeting began at 4:02 pm GMT (10:02 am CST)

The Executive Committee minutes from 10 July 2006 were unanimously approved.

The last IVPF monthly members' meeting took place 2 Aug at 7pm CST (1am GMT). One member attended. Questions about walk registration, materials, and vp in general were answered.

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
 - IVPF received a letter from the editor of the Green Journal in response to our commendation for the April 2006 CME expert opinion paper they published on vasa previa. The editor stated that they would not be publishing our letter due to priority reasons - they have too many to publish, but she thanked us for our input. Amy drafted and sent a response thanking them for their consideration but expressing our dismay at not having greater priority due to the importance of recent vasa previa findings.
- Vice President
 - Phil Millard has accepted the post of Vice President. Welcome Phil!!

- Secretary
 - IVPF SigmaChat rooms are up for yearly renewal. Cindy has contacted the company requesting that they continue to donate the 5 rooms that we have with them.
 - SophiesWalk.org was renewed on 12 July at a cost of 17.61 pounds.
 - The minutes from the last 5 Executive Committee meetings have been uploaded to the IVPF website at <http://IVPF.org/minutes>
- Treasurer
 - USA
 Donations and interest: \$0.00 (no report given)
 Expenses: \$0.00
 Total cash on hand: \$43,236.74
 In-kind donations: \$ 0.00
 Thank-you notes sent to donors: 0
 - UK
 Donations and interest: £ 0.00
 Expenses: £ 0.00
 Total cash on hand: £ 604.39
 In-kind donations: £ 0
 Thank-you notes sent to donors: 0

Membership:

- Phil Millard is in the process of upgrading the Forum. Upgrades are not online yet.
- Christi Rees has requested participating membership.

Public Relations:

- Summer 2006 newsletter went out 27 July.
- Press Release on April 2006 ACOG article was proofed and changes are being made.
- Melissa Floor contacted Cindy regarding an article on vasa previa that she hopes to have published in some nursing magazines, nurseweek, advance for nurses, etc. Cindy responded to her request for information and included PDFs of the 2 most recent articles on vp, the press kit, and the IVPF PR article. Cindy also offered to send her IVPF print materials and brochures for her event.

Research:

- No report given.

Fundraising:

- Due to health reasons, Sue Miller will not be able to take over as Fundraising Chair at this time.
- The Jerome Group bid for Sophie's Walk brochures was 1,000 - \$1,068; 2,000 - \$1,271; 4,000 - \$1,349; 6,000 - \$1,422. Victoria got a bid from PK Broward to print 5,000 brochures for \$650. This bid was approved by IVPF Exec and accepted. Jerome agreed to supply the electronic files and they have been forwarded to PK Broward. 5,000 walk brochures have been ordered from PK Broward.
- Memorial donation cards were customized and emailed to a contact who called the IVPF about his granddaughter's funeral.
- Several emails, including a sample "save the date" sample email about the walk have been sent to walk captains, IVPF participating members, and the Vasa_Previa email group. 17 cities now have registered walkers. Numerous updates to the online walk pages have been made.
- As part of Jennifer Fredrick's legacy to her son, Lucas, the IVPF is now offering "Lucas' Legacy

Angels" for free through the IVPF store to anyone that requests one (limit of one free angel with a \$1 charge for postage - PayPal would not accept a \$0 payment). Additional angels are available for purchase at the regular price. IVPF will continue to purchase angels from Jenny and she will donate additional angels to us based on requests received for the free ones. Store listing for Lucas' Legacy Angels is based on Lucas Legacy page on his website: <http://lucas-fredrick.memory-of.com/> There is a link in the store to his website as well as links to both the IVPF store and Lucas website on Jenny's walk page. So far 2 Legacy Angels have been sent out.

- Victoria's Secrets cookbook is in the store. This listing includes 3 pages of the inside of the cookbook. One set of 5 wristbands have been ordered, processed, and shipped.
- It was suggested and agreed that we set up a Yahoo group for Sophie's Walk Captains. That way automated reminders can go out and it will be easier to keep the captains list available online.
- It was suggested that IVPF sell beach bags at the larger walks. This item is pending.
- Community Health Charities is concerned about a new Combined Federal Campaign rule that is being proposed. They have sent out a call for letters of support from their member charities. Their sample letter has been used by the IVPF to do this. Letter was sent out on 5 August and also forwarded to CHC.

Education Committee Report:

- **Education Committee meeting** reminders have been set up for 20 Aug and for the second Sunday of every month at 8pm GMT (2pm CST) thereafter and to repeat every other month in the IVPF (newsletter) email group calendar and in the Vasa_Previa email group calendar. Reminders will go out 7 days and 2 days prior to each meeting. Meeting reminder text has been forwarded to Daren so that he can personally send this reminder to all Education Committee members prior to each meeting. We have no automated system to do that unless we set up another Yahoo group specifically for just Education Committee members. It was suggested that we set up another Yahoo Group for the Education Committee to facilitate communications.
- **Doctors Database:** Work is continuing on the worldwide database of doctors who are able to diagnose vasa previa and this was added to considerably in Barcelona.
- **Acronyms:** Daren has yet to allocate this task. NOTE: Cindy has streamlined the EXEC minutes to include all these events and the acronyms for all the medical organizations are now always included, as well as links and dates to each event.
- **Wycombe General Hospital event:** 17 May 2006 at 10 am GMT. Daren Samat gave a talk on his vasa previa experience during an "Education Day" lecture at this facility. The Trust held a "Review of the Management of Vasa Praevia". It was attended by at least one obstetric professor and several obstetric consultants and midwives (in total about 45 – 50 staff). Presentations were made by Professor Impey (Head of the Obstetric Regional Referral Unit, John Radcliffe Hospital, Oxford), and a review of all NHS policies was presented by an obstetrician from the Obstetric Department Wycombe General Hospital. Daren Samat also made a presentation and put a strong case for the routine screening for vasa previa and this was very well received. The meeting concluded that as a full review was in progress, there would be a need to consider all the data when it is complete, therefore a follow up has been set for some time this summer 2006. In the meantime the NHS Trust plan to follow up on the meeting and they are undertaking a complete review of the management of VP throughout the NHS, this includes a survey of all obstetric departments in the UK. The aim is to publish the results in a British Medical Journal.
- **5th World Congress in Fetal Medicine** 25-29 June 2006, Barcelona Spain: http://www.fetalmedicine.com/wcfm_intro.htm Daren & Natalie Samat have forged a close professional relationship with Professor Kypros Nicolaides and other doctors of the Fetal Medicine Centre and Foundation, 137 Harley Street, London, W1G 6BG, England. We hope this will develop so that Professor Nicolaides will champion our cause. Daren's overwhelming

feeling is that this is a conference that IVPF should make every effort attend annually, as we were able to make good contact with the vast majority of the 1,000+ specialist obstetricians (from 65 countries) who attended. Furthermore, this year, most delegates left the conference with VP ringing in their ears, as the final speaker Professor Waldo Sepulveda, lectured on routine screening for velamentous cord insertion (and in part VP) and specifically referred to IVPF's presence. As Daren was invited to attend this conference personally, and so the IVPF incurred no conference expenses at all, all expenses of this trip were wholly incurred by Daren & Natalie Samat. It is hoped that we will be invited again next year (to be held in Croatia). A big thank you to Daren and Natalie for funding their travel at their own expense!

- **National Childbirth Trust (NCT) Conference** 1-2 July 2006, Brighton, England: http://events.nct.org.uk/event_info?event=2 Together with Lisa & Anthony Paine, Natalie and Daren Samat attended and exhibited an IVPF stand. We also made a very useful contact with a Professor James Walker (Head of Obstetrics at St. James' Hospital – Leeds) who was able to provide us with some valuable advice. We were approached by 3 separate delegates who informed us that they had suffered undiagnosed vasa previa (all with predictably dire consequences – one had lost all three of her triplets) and a further 4 delegates who told us that they currently had a student in their class diagnosed with vasa previa. Two things arise; (1) perhaps vasa previa is not so uncommon [and though this was obviously not a truly representative sample – it was odd to have at least 9 cases of VP in the whole delegation of 600 people], but more importantly it is NOT as uncommon as people (especially doctors) make it out to be. We suspect that the occurrence rate might even be greater than the currently accepted 1:2500 (2) it seems that there may be an increase in prenatally diagnosed cases in the UK? All who attended found this conference a very worthwhile exercise and experience, perhaps worth repeating next year.
- **Challenges in Antenatal Screening & Pregnancy Care** 17 July 2006, London. Daren will look into the details. <http://www.arc-uk.org/conference.html> Flyer for event: <http://www.arc-uk.org/arc-conference.pdf> This conference was attended by approximately 200 delegates, mostly consultant obstetricians and specialist obstetric registrars and midwives. The reason why so many delegates attended was because of the impressive list of speakers that included Sir Muir Grey [Head of UK Screening Policy makers the NSC], Dr. Lyn Chitty [chair of the Fetal Anomaly section of the NSC], Professor Nicolaidis, and Professor Jason Gardosi [Perinatal Institute of West Midlands]. None of these speakers left without speaking to Daren and though much of the discussion was very positive, it was evident that there is still much to do to convince some of people (with the exception of Professor Nicolaidis) that diagnosis of VP should become part of the routine anomaly scan. This was a very worthwhile event and again Daren was able to get himself “invited”, hence IVPF incurred no exhibitor's expenses. Most importantly Daren was able to make a very useful contact in the conference organizer Joanie Dimacivicus who was the founder of ARC. Daren will be meeting with Joanie in the near future to discuss who we should look to as “targets for patronage” in our quest to change the protocols in the UK – it seems Joanie knows everyone personally.
- **International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) 16th World Congress** 3-7 September 2006 in London, England. <http://www.isuog2006.com/> IVPF is confirmed for this event. Daren Samat and Phil Millard have agreed to staff the booth. Amy Gaghagen will also be attending. Yinka Oyelese will be attending. Rooms for Phil and Amy have been booked. Amy will bring the necessary materials with her for this event and leave the extras with Daren.
- **Fetal Medicine Foundation of America (FMFA)** <http://fmfaus.meetingpro.info/registrants/MasterSeries06/MasterSeries06.htm> Next event is 3-5 November in New York. After that is 30 November - 3 December in Ft. Lauderdale which Victoria will be attending.

- **APGO is the 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. A doctor at the ACOG conference suggested IVPF attend. Amy will write to the contact about an application.
- **International Society of Obstetric Medicine (ISOM):** 15-17 Nov 2006 Taking place at the Royal College of Physicians in London:
http://www.isomnet.org/ObMed_01/default.cfm?sect=News&id=2&EID=84 Medical Complications in Pregnancy:
<http://www.prossl.com/symposiassl/eventprog.asp?year=06&evcd=15> Registration form:
http://www.isomnet.org/obmed_01/sections/News_events/supdocs/RoyalCollegePhysicians2006.pdf Contact info: The Symposium Office +44 (0)20 7594 2150, sympreg@imperial.ac.uk
 This event is approved pending cost information and volunteers to staff.
- **Perinatal Society of Australia and New Zealand's (PSANZ) 11th Annual** Conference taking place in Melbourne, Victoria, Australia 1-7 April 2007. Its been suggested that IVPF attend and arrange a speaker for this event. <http://psanz07.eventplanners.com.au/> If we can arrange a speaker the paper will have to be submitted by August 2006. Since we have a couple of hospitals wanting vp presentations in Australia, perhaps we can arrange them at the same time as this meeting. Natasha Donnelly will be contacting Professor Morris who is the PSANZ coordinator for NSW Australia on behalf of the IVPF.
- **American College of Obstetricians and Gynecologists (ACOG) Conference**, San Diego, CA, USA, May 2007: <http://www.acog.org/acm/program/welcome.cfm> Letters to doctors from the May 2006 event are on hold pending the arrival of study reprints. Reprints have been received and information forwarded onto Jeannette Schwartz for processing.
- **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 This event is approved pending cost information and volunteers to staff.
- **Mailing:** Mailing has been quite successful. Cost per each hospital/doctor contacted was \$1.63 each. There have been about a dozen returned as undeliverable. IVPF has received 17 communications from hospitals and physicians requesting more brochures or information on educational programs for OB departments. 14 of them are requests for educational programs (grand rounds). 2 requests for a grand rounds speaker are from Australia, 1 from Canada, and the rest from the USA. Yinka Oyelese MD has agreed to do them. A mailing list from the UK for the next round of mailings is pending.
- **International Woman's Day 2007:** Carol Prentice to continue look into raising IVPF's profile and awareness of vasa previa at this event. Current status unknown.
- Jerome has supplied the IVPF with the electronic files for the IVPF brochure and bookmark and the Sophie's Walk brochure, enabling us to hand them off to printers in other countries. This will save us money on shipping the materials overseas.
- **Australian Web Directory Well Being Spot** Cindy Paris was notified that <http://NathanParis.com/vp.htm> and the IVPF have been added to their pregnancy and birth complications category. These were unsolicited additions!
<http://www.wellbeingspot.com.au/health-wellbeing/pregnancy-and-birth-complications/vasa-previa.cfm> Cindy has submitted <http://SophiesWalk.org/walk> to the same category.
- A packet of information was sent to a contact, at his request, who's granddaughter passed away from undiagnosed vasa previa last week.
- Packets of the IVPF mailing have been sent to 2 doctors in Australia at Natasha Donnelley's request. An additional packet has been sent to Natasha with additional reprints and IVPF

materials for her vp outreach activities.

- Additional packets of the IVPF mailing have been sent to 8 doctors in Canada at Claudia DiVirgilio's request. An additional packet has been sent to Claudia with additional reprints and IVPF materials for her vp outreach activities.
- **IVPF "Essential Reading on Vasa Previa"** (the "bible" thing), we have learned that we will not be able to get permission to reprint the necessary medical journal articles ourselves into a bound publication by the IVPF. We have considered the idea of using abstracts instead, but the April 2006 ACOG abstract (and the most important piece to date) is very poor in relation to vasa previa. (The article itself is GREAT!) Volunteers are welcome and needed to go through the medical resources on the IVPF site, look up the articles online, and submit them and some recommendations for this project.
- **IVPF In-Service Presentation Materials:** Lisa Paine and Jenny Steckler are liaising on a CME document. Lisa has reported that she is not quite sure of the form that this is to take. Daren has suggested that it should be similar to the GE Capital Healthcare website document he recently circulated. Cindy has reported to Daren that we need to start with a powerpoint presentation and that she's already spoken with Lisa about this. Lisa is to get the AIUM presentation from Daren and use that, information from the latest papers and research, and the IVPF ppt to use as a base. IVPF will supply pictures as the pictures in the AIUM ppt are copywritten. This will get us started on this project. After that it will be forwarded to the IVPF medical advisory board. Criterion formats (paperwork involved) from a couple of mainstream CME sources have been sent to Jenna Steckler and also to Lisa.
- **Jenna Steckler's Grand Rounds Set Up Guide** has been uploaded to the IVPF web space at <http://IVPF.org/Docs/GrandRoundsSetUp.PDF> There is a link to the document in the IVPF online Office Space.
- **Oprah Winfrey Show:** Kara Giammarino is working on a project of raising awareness through the Oprah Show. Current status unknown. Kara was to write up a letter. Cindy hasn't heard back from her on this.
- **Child Birth (Lamaze) Classes** and how VP awareness could be raised in these classes. Lora Beth Sabbatini agreed to tentatively look into this and see if there was a way to reach a national contact. Current status – unknown. Note: the only way this can be achieved in the UK is via the NCT Conferences [done this year] - and/or by submitting a paper on vasa previa to the NCT for inclusion in the Antenatal Education Program, Daren has the details but no further action taken on this so far.
- **St. Mary's Health Center** (where vp angel Nathan Elliot Paris was born in 1996) contacted the IVPF requesting additional brochures to hand out to their patients. Cindy Paris responded personally on 12 July, sending 10 brochures, 10 bookmarks, and a copy of Nathan's story as well as offering to provide a speaker on vasa previa in honor of Nathan's upcoming birthday. There has been no response.
- **Stories:** Two new stories have been uploaded to the website.

Support Committee Report:

- Three Lucas' Legacy Angel pins have been requested and sent out.
- Interest was expressed in getting the support materials compiled and online. As Kathy Blades is extremely busy right now, Cindy will contact Jackie Frith and try to get this project expedited.

Nominating Committee Report:

- A request for additional committee members went out to IVPF@yahoogroups.com, all IVPF participating members, and the Vasa_Previa email group on 27 June 2006 and again a month later. Carol Prentice, Michele Dillard, Darcie Fredrick, and Jeannette Schwartz have responded

and are willing to sit in this committee. Phil Millard, Debi Pederson, and Cindy Paris are also members of this committee.

Old Business:

- Lehman Grant: Amy is working on completing this project. The Spurgeons' are very disappointed that Lehman hasn't donated to us yet. It was mentioned that we need to create a budget for this item. Cindy and Amy will meet this week to create one.
- Directors Insurance: Other requests for firm quote(s) have been sent out to additional companies. Amy will contact Jeannette to find out where we stand on this.
- Medical Advisory Board: Invitations have been sent to an additional 6 potential members of the board. IVPF has received no responses yet. Amy will send out follow-up emails.
- Referral links to Professor Nicolaides <http://www.fetalmedicine.com/> and <http://www.fetalmedicine.com/f-fmc.htm> on the IVPF website as a website referral: This link has been given out several times to diagnosed people from the UK needing referrals. Daren would like to see this item actioned ASAP. This was done today, a new page was created and uploaded to <http://IVPF.org/resources/resources.htm>
- Newsletter: Done. Sent out to members on 27 July 2006.

New Business:

- It was moved and duly seconded to approve Christi Rees as participating member. Motion passed unanimously.
- It was moved and duly seconded to approve IVPF attendance at the Perinatal Society of Australia and New Zealand's (PSANZ) 11th Annual Conference, 1-7 April 2007, Melbourne, Victoria, Australia, pending the receipt of cost information and volunteers to staff the event. Motion passed unanimously.

The next regular IVPF Executive Committee meeting will take place on Monday 28 August 2006 at 4:00 pm GMT (10:00 am CST, 11:00 am EST).

Meeting Adjourned at 4:59 pm GMT (10:59 am CST)