

<b>MINUTES FOP ACTION UK</b>		
<b>COMMITTEE MEETING 16<sup>TH</sup> FEBRUARY 2012.</b>		<b>ACTION REQUIR -ED BY</b>
<b>PRESENT</b>		
President Chairman Head of FOP Research at Oxford Medical Advisor Development Officer, FOP Research Fund FOP Community Member Medical Advisor FOP Research team: Head of FOP Research FOP Post-doc researcher FOP Post-doc researcher FOP Post-doc researcher	Mr RA Simcox (RAS) – on behalf of Roemex Mrs. Sheryll Hadley (SH) Professor Jim Triffitt (JF) Professor P Wordsworth (PW) Ms Frewenyi Kidane (FK)  Mr Chris Bedford-Gay (CBG) Dr Roger Smith (RS)  Dr Alex Bullock (AB) Dr Caroline Sanvitale (CS) Dr Ellie Williams (EW) Dr Georgina Mosedale (GM)	
<b>APOLOGIES</b>		
Kelly Sanderson – Press/Website Julie Hopwood – Publicity/Fundraiser Marian Granahan – Finance Officer		
<b>MINUTES OF PREVIOUS MEETING</b>		
^ This was the first official meeting to be minuted, therefore no previous minutes to be agreed.		
<b>THANKS</b>		
^ SH said a special thank you to everyone for attending from FOP Action UK.		
<b>OBJECTIVES:</b>		
1) To meet the new Research Team and gain further understanding of the research to date and the next steps to be take 2) To establish the level of fundraising required in order to further support the current and future research. 3) To elect new committee members to work as a team to develop awareness and undertake fundraising 4) To create an action plan in order to meet the set fundraising budget		
<b>1) RESEARCH TEAM, RESEARCH TO DATE &amp; NEXT STEPS</b>		
<ul style="list-style-type: none"> <li>• Research team introduced by JT as AB, EW, CS and GM.</li> <li>• AB gave a presentation on research to date and the next steps which is summarised as follows:</li> <li>• The ACVR-1 gene was discovered in 2006. A mutation in this gene causes FOP. The discovery of the FOP gene provides a highly specific recognised target for future drug development.</li> <li>• Research efforts are now focussed on a treatment or cure that will block or bypass the genetic trigger which results in extra bone growth.</li> <li>• This drug discovery cannot be done alone – it is an international effort.</li> <li>• Our lead drug K02288 is currently being tested on cell systems and mouse models.</li> <li>• There is a possibility that a Phase I trial is 2 years away, but it is impossible to say.</li> </ul>		

<ul style="list-style-type: none"> <li>• Funding for this research comes partly through SGC - a charitable public-private partnership which supports the discovery of new medicines through open not-for-profit collaboration. This is added to donations from RAS and Roemex, and fundraising.</li> <li>• CS's contract ends end-Sept 2012, but she would like to extend this if funding is available. EW's and GM's contracts end Oct and Dec 2013.</li> </ul>	
<p><b>2) LEVEL OF FUNDING REQUIRED</b></p> <ul style="list-style-type: none"> <li>• It was put forward by RAS and agreed by committee that £120,000 is needed to fund the current research, and this funding needs to be in place by January 2013.</li> <li>• FK presented a graph of FOP donations from 2001 to 2011. 2008 was low at £11,000, but 2009 was particularly high at £36,000. This was attributed to donations from the US. Last two years 2010 and 2011 have been fairly constant at £26,000.</li> <li>• Donation from RAS and Roemex has funded 2 post-doc research posts for EW and GM.</li> <li>• RAS spoke to announce that Roemex has lost a major client. He will honour and guarantee the funding for 2012, but cannot guarantee to underwrite the funding from 2013 onwards at present.</li> <li>• RAS suggested that a substantial effort is needed to increased fundraising from £26,000 a year to £120,000.</li> </ul>	
<p><b>3) ELECT NEW COMMITTEE MEMBERS</b></p> <ul style="list-style-type: none"> <li>• CBG was welcomed and elected as a new member of the committee to help with raising awareness and fundraising.</li> <li>• RAS emphasised the importance of motivated, committed team members and the need for all members to be present at these meetings.</li> </ul>	
<p><b>4) ACTION PLAN TO MEET £120,000 FUNDRAISING BUDGET</b></p> <ul style="list-style-type: none"> <li>• RAS said that while this was daunting, it was possible and suggested that 20 different people/families or projects raising £5000 would substantially cover the costs.</li> <li>• Previous fundraising efforts were praised by the committee - such as Land's End to John O'Groats which raised nearly £6000, and Julie Hopwood's friend's dance studio raising £2000.</li> <li>• CBG emphasised that responsibility for fundraising cannot be placed on the families of sufferers alone, as some have done a great deal of this.</li> <li>• RAS suggested that in addition to these projects we need to target personal/business contacts for considerable donations.</li> <li>• AB clarified that donations from RAS and other fundraising, was doubled from a University of Oxford grant, but this grant was not solely for FOP.</li> <li>• RS highlighted that research into FOP treatments/cures has other applications e.g. osteoporosis and bone formation. This wider applicability should be emphasised in Grant Applications and will increase the range of grant applications that can be applied for.</li> <li>• FK added that Gift Aid should be claimed on all donations from UK tax-payers. This would increase the value of donations by 20%.</li> <li>• SH suggested a Ball in Oxford could be successful and certain members' affiliations to Oxford colleges could be helpful with this – St Catherine's and Green Templeton Colleges discussed.</li> <li>• JF mentioned that FOP Italia receive a great deal of money from Telefon. Perhaps we could get involved in Children in Need and Red Nose Day fundraising.</li> <li>• FK added that an option button to donate money on E-bay could raise money and awareness.</li> <li>• CBG added a similar option with Amazon is possible where a project receives a percentage of the money spent.</li> </ul>	

<p><b>WEBSITE/ MEDIA</b></p> <ul style="list-style-type: none"> <li>• It was agreed that these minutes would go on the FOP Action UK website</li> <li>• Website was thought to be working well. CBG emphasised how helpful he and his family had personally found it.</li> <li>• CBG suggested that he will work on heightening the website in the results generated in search engines from specific “search terms” such as symptoms. This will aid public awareness of FOP.</li> <li>• PW confirmed that he receives referrals from Paediatricians around the UK requesting he meets suspected/new patients</li> <li>• PW confirmed that the internet is a useful medium to assist diagnosis, with Doctors using Google search engines, together with English and American texts</li> </ul> <p><b>AOB</b></p> <ul style="list-style-type: none"> <li>• PW confirmed that a Symposium for rare bone disorders would be possible at the Nuffield, to be arranged during a working week for early 2013.</li> <li>• PW confirmed medical conferencing facilities would be available</li> <li>• SH expressed concern that when e-mailing patients, some messages had not successfully delivered</li> <li>• CBG stated he would contact IFOPA regarding a current, up-to-date directory</li> <li>• PW stated he may be able to give names of additional patients, however, we must take caution here over Data Protection Act, medical confidentiality.</li> <li>• CBG asked AB if any items of laboratory equipment were needed, since CBG had been given possible offers of funding for equipment.</li> <li>• AB stated he would confirm with CBG</li> <li>• SH thanked all attendees and expressed much thanks and appreciation from all of the FOP community for the commitment and strenuous efforts of the research, medical and finance teams.</li> <li>• SH and CBG confirmed they would be arranging an urgent FOP ACTION COMMITTEE meeting in the Manchester area, for patients living further north.</li> <li>• Close of meeting</li> </ul>	<p><b>CBG</b></p>
<p><b>DATE OF NEXT MEETING – TO BE CONFIRMED</b> <span style="background-color: yellow;">                    </span></p>	
<p><b>MINUTES APPROVED BY THE COMMITTEE</b></p> <p>S. HADLEY</p> <p style="text-align: right;"><b>Date: Monday February 20<sup>th</sup> 2012</b></p>	