



Minutes of Rare Disease UK's Annual General Meeting

Monday 13th September 2010

Nation Council for Voluntary Organisations
Regent's Wharf, 8 All Saints Street, London, N1 9RL

Management Committee members in attendance:

Alastair Kent - Chair – Genetic Alliance UK
Mark Barrett – Orphan Diseases Industry Group (ODIG)
Steve Potter - Treasurer – Orphan Diseases Industry Group Partnership (ODIGP)
Laura Gilbert – Research Consultant
Dr Peter Corry – Bradford Hospitals
Dr Marita Pohlschmidt – Muscular Dystrophy Campaign

Via Teleconference:

Marie McGill – Scottish representative - Single Gene Complex Needs project
Dr Stephen Jolles – Welsh representative - Cardiff and Vale University Health Board

Apologies:

Becky Purvis – Secretary – Association of Medical Research Charities
Dr Fiona Stewart – Northern Ireland representative – Belfast City Hospital

Others in attendance:

Stephen Nutt – Rare Disease UK Secretariat
Melissa Hillier – Rare Disease UK/Genetic Alliance UK
Helen Munroe – Advisor to Rare Disease UK – Advocate
John Chandler – PSP Association
Lara Bloom – Ehlers-Danlos Support Group
Alan Thomas – Ataxia South Wales
John Solly – Myrovilitis Trust
Glenn Irvine – Advocacy for Neuroacanthocytosis Patients
Drew Greaves – Shire

Apologies received:

Richard West – Behcet's Syndrome Society
Timothy Barrett – University of Birmingham/Birmingham Children's Hospital
John Holt – West Berkshire Neurological Alliance
Susan Walsh – Climb
Stuart Tanner – University of Sheffield
Dr Sophie Duport – The Royal Hospital for Neuro-disability
Kathy Oliver – International Brain Tumour Alliance
Louise Derbyshire – Contact a Family

Rare Disease UK

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in Scotland (no. SC039299).

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1. Welcome and apologies

The Chair welcomed attendees to the meeting and passed on apologies.

2. Report from the Chair on the activities of Rare Disease UK (RDUK)

- The Chair gave an overview of RDUK's activities over the period July 2009 – June 2010. The Chair cited some of the main achievements as being:
 - Holding three successful parliamentary receptions to mark Rare Disease Day 2010
 - Building good links with officials in each of the four health departments and key figures within all four NHSs
 - The establishment of five Working Group which have developed initial recommendations for a strategy for rare diseases
- The Annual Report was presented and was received by the Management Committee.
 - Proposed: Marita Pohlschmidt
 - Seconded: Steve Potter
- The Secretariat informed attendees that the text of the report would go to the designers and hard copies of the report would be distributed when printed.

3. Consideration of the accounts

- The Management Committee received copies of the full accounts for the period from 1st January 2009 – 31st December 2009 and the projected accounts from 1st January 2010 – 31st December 2010. This was due to the reporting period for RDUK being different to that of Genetic Alliance UK. RDUK's accounts would be audited as part of the Genetic Alliance UK accounts.
- The Committee questioned the projected shortfall for the period 1st January 2010 – 31st December 2010. The Chair responded that there is a shortfall due to increased activity, for example, employing another full-time member of staff which was not budgeted for at the beginning of the year. The shortfall would be met by Genetic Alliance UK in demonstration of the commitment of the organisation to RDUK.
- The Treasurer thanked Allison Vitalis, the Genetic Alliance UK Finance Officer, on the clear and comprehensive accounts and congratulated RDUK on the financial prudence shown.
- The accounts from January 2009-31st December 2009 were accepted. The projected accounts for 2010 were noted.
 - Proposed: Peter Corry
 - Seconded: Mark Barrett
- It was discussed for how long RDUK would continue to seek funding for. The second phase of RDUK's work would come to an end following the launch of the recommendations and report on Rare Disease Day. The third phase would then entail maintaining the pressure on government to draw up a strategy. Following this, the implementation of a strategy in practice is crucial and the Chair was of the opinion that a strategy would not be embedded before 2013. As a result funding would need to be sought until 2013 and then the situation reviewed.
- The Management Committee agreed that the membership fee for industry members should be held constant at £7000.

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4. Election/re-election of the members and officers of the Management Committee

- The Chair reported that each member of the Management Committee is elected for a period of 3 years and all have agreed to stay on – as a result there were no vacancies on the Committee.
- Steve Potter agreed to remain as Treasurer and the Chair reported that Becky Purvis has agreed to remain as Secretary.

5. AOB

- The Chair indicated that John Chandler had raised an issue in advance of the meeting that he would like to discuss.
- John Chandler raised concerns about the issue of RDUK's relationship with the Specialised Healthcare Alliance (SHCA) and whether the existence of two organisations diluted the impact of the message. John Chandler expressed concern that:
 - Having two relatively small organisations both funded by the pharmaceutical industry is fragmenting resources.
 - Whilst recognising the two organisations do have different objectives he also feared that the focus could be lost.
 - There would be 2 APPGs dealing with rare diseases.
- The Chair countered that:
 - RDUK has an ongoing relationship with the SHCA and both organisations meet regularly to ensure that work is mutually compatible.
 - RDUK's remit is to campaign for the effective implementation of a strategy for rare diseases.
 - RDUK works across the whole of the UK as opposed to England.
 - The emphasis of RDUK extends to research and development.
 - John Murray (Chief Executive of the SHCA) inputs into RDUK's work through the Working Group on Commissioning and Planning.
- John Chandler remained concerned that having two organisations were diluting the message of the rare disease community, whereas members of the Management Committee felt that a stronger message comes from having two organisations.
- John Chandler whilst commending the work in the Devolved Nations expressed that these amount to a small amount of the total population of the UK. He believed that the income of the two organisations could be combined and a more effective organisation established.
- Stephen Jolles and Marie McGill affirmed the importance of RDUK's work in the Devolved Nations.
- The Chair stressed the difference between the two organisations: the SHCA campaign for the effective implementation of the Carter Report; Genetic Alliance UK were heavily involved in campaigning for the Commission Communication and Council Recommendation leading to the establishment of RDUK to campaign for a strategy for rare diseases. Commissioning would be an important part of a strategy, but only one element.
- The Management Committee was of the opinion that while ensuring that there was maximum communication and collaboration on relevant issues, at present the greatest impact could be achieved involving partnership with all stakeholders from the existence of the two organisations.

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