rare voices
AUSTRALIA

Executive Director's Report

4th Feb 2013- 30th June 2013

Acting Executive Director; Megan Fookes

Rare Voices Australia appointed its first staff member; Acting Executive Director on 4th February 2013. Megan Fookes works at the office as RVA's first Executive Director paid part time 3 days a week. Rare Voices Australia sub-lease a small office at Genesis Taxation in Castlecrag NSW. The new office was offered to RVA for a small rental fee.

Goals

The objects of the company are to:

(a) To provide a unified voice to improve the lives of all Australians affected by rare conditions;

(b) Develop and provide strategic input into planning for rare diseases at both state level and national level;

(c) Advocate for the implementation of services and support for people suffering from rare diseases;

(d) To foster and support research into rare diseases including but not limited to research into the prevention of rare diseases and research into methods for alleviating the suffering of people with rare diseases;

(e) Maintain links with international organisations in order to further the other objects of the company; and

(f) To carry out such other functions and purposes which are necessary or incidental to the other objects of the company

Short Term strategies / activities / Projects

Project Objectives

1. A number of different projects are outlined in this document. All have as their primary objectives;

2. To raise awareness of rare diseases as a national health priority.

3. To advocate for the establishment of a national rare diseases registry.

All of these projects are aimed at engaging with the Australian rare disease community and giving them a chance to be heard in a number of innovative ways. Rare Voices Australia is a new organization with limited resources at present. Therefore all of these projects will need considerable lead time in order to be planned, managed, implemented and evaluated effectively.

Short Term Goals

Establish the RVA National Office

- An office sit was identified at Suite 2/3 The Postern Castlecrag at an affordable sub-lease monthly rate. Office equipment i.e. 2 desks, drawers, chairs, filing cabinets, book shelves, photocopier is included as well as a meeting room, toilets, kitchen, disability ramp access and car parking. It is located 10 mins North of Sydney CBD in walking distance to buses and public transport. Office set up included; purchase equipment, licensing computer programs, phone line/ mobiles, office rental.

Prepare PR Materials

- PO Box – set up for all mail to RVA. This is located adjacent to RVA office.
- Printed collateral – business cards, RVA Fact Sheet and RVA poster via a local printer.
- RVA pop up poster X 2 – take to meetings and events

Website

RVA website launched 27th February 2013. Stage 1 involved writing the content and uploading material relevant to the current rare disease situation of Australia. Stage 2 will involve furthering this work and linking it to social media. RVA will train its staff to use this content's management system once an office administrator is in the office. Until then, Loft have offered to upload any materials pro bono including regular news items.

Communication

RVA communicates via its Facebook page, email and monthly E Newsletters. Currently RVA Executive Director prepares all the materials and these are uploaded each month by Loft.

E Newsletters –

A regular monthly E Newsletter template was set up via Loft Graphic Artist.

Newsletter shares information about current local, State, National and International rare disease news. Information talks to a range of issues including; Rare Disease Policy matters, access to rare disease treatments, research, patient organisations, projects and events managed by RVA.

RVA needs to formulate a Communication Strategy to ensure communication with RVA supporters is consolidated via all its communication channels and tying the E News with social media.

Social Media

RVA wrote a Social Media Policy. The Facebook page has been well received by the rare disease patient community with 900+ friends regularly in contact with RVA. It has been a fast and effective means of instant communication with the rare disease patient community.

Long Term Goals/ Projects

RVA and Pharmaceutical Industry Round Table Meetings – quarterly

First meeting was held at Genzyme offices on 27th Feb. Introducing current strategy, work, future endeavours and confirm policy of working in collaboration with industry policy. 15 Companies will have 1-2 in attendance and include: Bayer, Pfizer, Alexion, Biomarin, Genzyme, Shire, Eily Lilly, Actelion, Roche, Abbott, GSK, Novartis, Protalix, Merck and Vertex

Second meeting was held at Shire offices on 23rd May 2013

The focus of this meeting was to finalise the working relationship with industry and talk to the Proposal of funding RVA.

RVA plans these meetings to be hosted by a different company each time (simply because RVA doesn't have the capability of hosting an event of this size) on a quarterly basis.

Future meetings will be planned on key topics such as access to Orphan Drugs in Australia and other areas of need and interest of both parties.

All dealings with the Pharmaceutical Industry are strictly in accordance with the Medicines Australia code of conduct and our own Dealing with Industry Policy.

Campaigns / Projects

RVA Parliamentary Launch – House of Representatives Courtyard – BBQ lunch 20th March. This event marked the official launch of Rare Voices Australia, the need for a National Rare Disease Plan and to mark International Rare Disease Day 2013 (Feb 28). All attendees received an RVA pin. Invites were sent to 270+ Ministers and Senators by official paper invitation from MP Jill Hall (Chair of Health & Ageing Committee) and an electronic version. RVA paid Ogilvy PR Health to co-ordinate this event.

RVA invited patients and patient organisations and pharmaceutical industry to have attendance. All patients wrote to the Federal MP asking them to meet with them at this event. This worked extremely well.

We have been strongly advised to continue this event on an annual basis.

RVA has partnered with WA Health to begin a national survey of the Australian experience of rare disease. This survey is based on the survey conducted by Rare Disease UK. The results of this survey will be used to add weight to the personal stories document when talking to policy makers and politicians.

RVA has also partnered with the Murdoch Children's Research Institute to conduct a survey of the national Neuromuscular Disease community.

Transition Forum – Saturday 23rd February / Sydney University

To document the issues experienced by young people living with rare diseases when transitioning from child health services to adult health services. To develop advocacy tools proposing changes / improvements in transition services.

The forum was organised by the Australian Paediatric Surveillance Unit in collaboration with The Agency for Clinical Innovation Transition Network, Rare Voices Australia and The Smile Foundation, and the TRAPEZE Transition Program.

International Rare Disease Day 2013

RVA hosted its first international rare disease day event in Canberra in March when all parties were present. Unfortunately the Australian political calendar doesn't align with the European Calendar. RVA will be hosting another event of this nature in 2014.

RVA held 2 meetings with philanthropic companies based in Sydney; Steve Waugh Foundation and The SMILE Foundation. Both organisations have grants and programs available to families who live with rare diseases. In Australia, there is a co-ordinating committee for Rare Disease Day and RVA has asked to join this committee. RVA prepared a proposal to the CEO's of SWF and SMILE outlining the need for an Event's Co-ordinator with a budget to co-ordinate an event that could be rolled out across Australia to enable the rare disease patient community opportunity to collaborate and unite on rare disease day. RVA is awaiting feedback from both groups.

Another team have proposed to hold a ball to mark rare disease day in Sydney. RVA have provided feedback to this group. This will be revisited in preparation and planning for next year's potential 2014 rare disease day event.

RVA have approached EURORDIS to be recognised as the official country representative for Rare Disease Day in Australia.

RVA have been asked to do an event at the Qld Hospital for rare disease day. This is being co-organised by Dr David Coman (RVA Board of Directors)

Projects

Project 1

To develop a phone 'app' and emergency wallet/purse card for people with rare diseases which directs clinicians to the OMIM (Online Mendelian Inheritance Man www.omim.org) listings. This will quickly direct health professionals to relevant information about the condition and may prevent potential interventions which are not recommended for that particular condition. This is particularly relevant for emergency department presentations.

Target audience, all Australians with a rare disease, and carers of children and adults with rare diseases. General practitioners, emergency department clinicians, medical specialists.

Evaluation

Formative.
Social media will be used to disseminate the project and to monitor its up take.

Summative.
The phone ‘app’ and the purse/wallet cards will be taken up and used by an increasing number of people with rare diseases.
RVA will hear less anecdotal evidence of emergency department treatment errors.
Anecdotal evidence of the use of the cards and ‘app’ will be distributed via RVA’s communication channels.

This project has not begun as yet, some preliminary research has been undertaken to investigate other ‘apps’ already in use, awaiting appointment of Media and communications staff member.

Project 2
Rare Voices Australia views this project as the next most important. This project also speaks to our stated objectives of awareness raising, educating and engaging with the rare disease community.
To provide the rare disease community of Australia, both patients and clinicians, with the opportunity to attend a workshop which gives them an understanding of the Pharmaceutical Benefits Scheme and the Life Saving Drugs Program in Australia. This workshop will illustrate how these programs are administered, how they impact on patients and their access to treatments.
To provide young Australians living with a rare disease the opportunity to engage in an educational workshop which discusses the issues faced in transition to adult care and possible solutions.
To provide these educational and interactive opportunities in every state and territory in the form a national rare diseases ‘road show’.

Target audiences.
All Australians who live with a rare disease, specifically those with an interest in the Life Savings Drugs Program and adolescents with a rare disease. Clinicians who have patients with rare diseases.

Evaluation:

Formative
People who attend the LSDP educational workshops will be asked to provide specific feedback on the value of the workshop to their understanding.

Summative
Long term this project will be evaluated based on the level of interaction between the participants in advocating for their disease specific treatments.
RVA will monitor the way new treatments are accepted onto the program and continue to support individual groups in their advocacy when sought.

Feedback from the workshops will be collated and published to provide information and advice to each state health department about the needs of the young rare disease community who are transitioning to adult care.

Numbers of people attending the education and participation workshops will be monitored. RVA will evaluate attendance rates and range of diseases represented.

A report giving feedback from these workshops will be published and made available on Rare Voices Australia's website.

Time Line
Plan, make bookings, and organize training manuals and facilitators- May-Dec 2013
Promote workshops, venues and dates Feb/March 2014
Workshop 1 in conjunction with Rare Disease Day 2014, Victoria Feb 2014
Workshop 2 Western Australia June 2014
Workshop 3 South Australia October 2014
Evaluate and Report Nov-Dec 2014
Other states in rotation in 2015.

This project has taken longer to establish than originally hoped, plans are underway for a Perth event in November 2013.

Project 3
This project also speaks to our stated objectives of awareness raising, education and engaging with the rare disease community.
This project will require considerable staffing and expertise levels. Rare Voices Australia therefore proposes that project be considered with a more long term view. See time line below.
To conduct a survey of the Australian experience of living with a rare disease, similar to that already conducted by Rare Diseases UK; 'Experiences of Rare Diseases: An Insight from Patients and Families 2010.'

To use the information gained to produce a high calibre document to be used in discussions with key policy decision makers at all Government levels.

Target audience, all Australians who live with a rare disease, policy makers at all levels of government.

Evaluation:

Formative.
The numbers of people who submit their personal 'stories' will be monitored.

The opportunity to be heard will be widely disseminated via RVA's website and social media, enabling widespread access by the rare disease community.

Summative.
The published document will be used as a marketing tool for Rare Voices Australia to tell the story of the rare disease experience in Australia.

The document produced and the data collected will influence the decisions made by policy makers. This will result in better access to information, timelier diagnosis, and higher standards of care.

The published report will be available on Rare Voices Australia's website and disseminated according to RVA's Communication Policy.

Time Line
Planning, web site design, testing and loading. Feb-March 2014
Stories are collected either via the website, (preferable option) or by personal interview April-August 2014
Stories are collected and collated, photo's taken Sept 2014
Final document sent to printers. Oct-Nov 2014

This project is well underway but has been held up by the need to address other pressing matters.

Project 4
This project speaks to Rare Voices objectives of education and advocacy for the Australian Rare Disease community.
To conduct a thorough review of the Life Savings Drug Program.
To write a position paper on the current status of the Life Savings Drugs program. This paper will investigate the conception of the LSDP, its history and the time-lines of clinical trials. It will examine all the phases involved in Australia in getting a treatment listed and .funded. From what happens internationally and locally by TGA, to listing on the PBAC who finally recommend funding at the LSDP level. RVA will review the current guidelines for each disease listed on the current program as well as the individual disease advisory committee terms of reference including other evaluative measures which determine patient access to the program. This review will further examine the moral and ethical reasoning behind its current status.

Target audience, policy makers, clinicians, all people who are already on the Life Savings Drugs Program and those who hope to be.

Evaluation:

Formative.
The research process will also inform the content of the LSDP education workshops. These will be constantly monitored by obtaining constructive feedback from those who attend.

Summative.
The LSDP discussion paper will be used in meetings with policy makers to advocate for improved transparent processes and access to orphan drugs for people with rare diseases in Australia.
The discussion paper will be available on Rare Voices Australia's website.
RVA will seek to have the paper published.

Time Line
Collection of research data and information. Present –Dec 2013
Writing and publishing of paper. Feb-March 2014

A great deal of background material has been collected, a member of the RVA board has been appointed to the Life Saving Drugs Program Post Market Review Committee. Therefore this project will be on hold until the review is completed.

Project 5

With the support of a number of small grants from a range of different companies Rare Voices Australia held a Parliamentary event in Canberra. This event also served to launch Rare Voices Australia. Rare Voices Australia has succeeded in obtaining the support of a national PR company to assist with its objective of raising awareness of rare diseases in the wider Australian context. In excess of 40 M.P's attended this event. This project is already underway but will need further administrative support to ensure continuity of contact with adopters and adoptees.

To reinvigorate the existing network of Friends of Rare Diseases in Western Australia.

To roll out the successful Politician Adoption Scheme currently in place in Western Australia across Australia.

The scheme will give people with rare diseases ready access to the Federal and State politicians in each electorate.

The role of the adopter is to keep the adopted politician informed of the issues affecting the rare disease community in Australia.

The people chosen to be the adopters will require regular briefings and be prepared to visit their local politicians at least twice a year.

A training workshop will be held in each state, in conjunction with the LSDP and Transition workshops. The Politician Adoption Scheme training would be held at the end of the sessions in a more informal relaxed environment.

Rare Voices Australia will develop the materials in conjunction with an experienced facilitator.

The Scheme allows people who live with rare diseases an opportunity to have their voice heard as well as giving them a role to play.

Patients become important 'pieces of the jigsaw' and have opportunity to advocate on behalf of themselves who are the only people with experience of living with their particular rare condition.

Target Audience, politically aware members of the rare disease community who are willing to accept the role of local advocate, all state and federal politicians.

Evaluation:

Formative.

Members of the rare disease community will come forward and offer to become advocates in their own regions.

Summative.

It is hoped that all federal and state politician will be 'adopted' by someone who has a personal connection to rare diseases.

Personal stories of advocate's interaction with Members of Parliament will be available on Rare Voices Australia's website.

The preliminary training for advocates will begin at the 2014 conference, also discussions are underway with Telethon Children's Health and Research Institute who are already running other patient advocacy training programs.