

## **RareX Conference, Gauteng 13/16 September 2018**

### **Tanya Collin-Histed reports...**

The 2<sup>nd</sup> RareX meeting took place in Johannesburg from the 13 – 16<sup>th</sup> September, organised by Rare Disease South Africa. The programme on the Thursday and Friday was open to all delegates and focused on science, genetics, policy and clinical care; and the Saturday and Sunday to patients and support groups only.

On the Saturday and Sunday the 'patient huddle' was attended by 30 patients/patient representatives from all over Africa including Ghana, Kenya, Zimbabwe, Lesotho, Tanzania, Nigeria, South Africa, and Botswana. 26 of the representatives had received bursaries to attend the patient huddle supported by Care Beyond Diagnosis (CBD), in collaboration with the EGA.

The patient huddle took on a workshop format led by a moderator who put in place the structure for the delegates to identify the challenges they face working in the rare disease community, the impact of those challenges and the root cause. From this, possible solutions were identified. At the end of this session, five main headings were identified: policy, data, training and education, support and stigma, and awareness and information.

As the participants were from different areas, countries and at different stages in their own organisational development, it was important for everyone to be able to meet their own challenges and also see how they could work collaboratively for Africa.

The next step involved everyone identifying an area that they were interested in working towards for their own group, then to take this forward for the rare disease community in their country, then as 'Africa' and finally how to work with other stakeholders. Each of these headings were broken down into actions to achieve in one, three and five years.

Finally, photographic evidence was taken for each group on those members that put themselves forward to be 'the strategic group' that would drive this forward for the rare disease community in Africa.

This was an inspiring meeting of like-minded people, all passionate about making a difference to the lives of rare disease patients and their families in Africa. It was recognised that the task is huge, but the exercise undertaken over the two day 'patient huddle' and the structures and networks that will be put into place from the meeting will ensure that there is a collaborative call to action.