

Case Study : EURORDIS acknowledged that South Africa had achieved the most coverage across all markets for this international campaign by agency, Grapevine Communications.

International Rare Disease Day 2014

Brief

International Rare Disease Day was first launched by EURORDIS (The Voice of Rare Disease Patients in Europe) and its Council of National Alliances in 2008, and is held on 28 February annually across the globe. This date was specifically selected due to when it's a leap year, the international event is held on the 29th day, this rare day serving to raise awareness of the plight of patients with rare disorders. Since its inception, more than 1000 events have taken place throughout the world, reaching hundreds of thousands of people and resulting in a great deal of media coverage.

In South Africa, where lack of medical infrastructure, research and support is a problem, The Rare Disease Society of South Africa (RDSSA) which was formed in 14 May 2013 has become a beacon of hope for families affected by rare diseases and provides the resources for medical care and practical aid for individuals suffering from life-threatening diseases.

The RDSSA's main objective for their first **Rare Disease Day** was to raise awareness among the general public, patients and their respective families, the medical fraternity, and decision-makers about rare diseases and their impact on patients' lives.

The theme for **Rare Disease Day 2014** in South Africa was 'care', the aim being to encourage everyone in the rare disease community to 'Join Together for Better Care' by raising funds and awareness for better care and improving rare disease patients' quality of life. With timely and accurate diagnosis and intervention, people with rare diseases could contribute significantly and positively towards society.

Rare diseases are disorders including those of genetic origin, and are life threatening or chronically debilitating diseases which are of such low prevalence that special combined efforts are needed to address them.

The RDDSA approached brand activation, entertainment and event company, Zinto Marketing Group to create a platform to gain traction and momentum for the month of

February to raise awareness and appointed specialist PR agency, Grapevine Communications to promote key messaging.

Agency Objective

Although rare disease patients form a minority of our society and receive minimal assistance and attention, the general public at large is unaware of the fact that there are more people affected by rare diseases than there are HIV/Aids and cancer patients in the world.

This statement alone set Grapevine the challenge and task to put International Rare Disease Day – 28th February on the South African calendar.

Our objective was to ensure that International Rare Disease Day was imprinted in the minds of the local population and on the national calendar like other registered international charities and organisations e.g., World Aids Day, Red Nose Day and Bandana Day and that rare diseases became top of mind, and care and on-going support for patients with rare diseases becomes a priority.

Scope of Work

Grapevine was fortunate to have an ambassador for the campaign, namely young Oscar von Memerty. This 18-year-old hip hop dancer and motivational speaker, who has overcome the serious physical challenges he incurred as a result of his rare medical condition, MPS 6 (Maroteaux Lamy Syndrome), which is characterised by dwarfism, among other symptoms was not new to media and was an excellent media spokesperson

Oscar had an incredible story of courage and hope to tell, and he used his life story, coupled with dance performances, to motivate and inspire the public about what it means to live with a rare disease in South Africa as well as the importance of receiving correct treatment timeously. Oscar embarked on a roadshow coordinated by Zinto Marketing Group that visited schools, university campuses, and shopping malls to deliver the important message about what people can do to get involved and help.

Grapevine first set out to secure pre-publicity to inspire people to join the movement and encourage their continued support. This was achieved by exploring all possible angles in the health and CSI sections of print publications and news reads on broadcast channels.

Grapevine communicated to all the SABC commercial and community radio stations that both the chairperson, Kelly du Plessis, who has her own story of plight with her first born, Juan diagnosed with Pompe Disease, and Oscar were available for interviews and subsequently garnered substantial airplay. Kelly and Oscar communicated key messaging about rare diseases, Kelly presenting a great deal of medical information and Oscar inspiring audiences with his story and being a role model for those affected by rare diseases.

The RDSSA in conjunction with Grapevine launched a social media campaign which became a significant element of the PR campaign. Grapevine alerted followers to interview slots, to join the roadshows and created content and viral conversations.

In addition, Grapevine actively promoted the fundraising element encouraging the community to SMS 'Rare' to 38232 to help raise funds for better care by donating R10 to buy a 'Jeans for genes' denim ribbon from selected stores countrywide and sporting their ribbon and favourite jeans on Friday 28 February 2014.

Grapevine also gave press a rare insight into the day in the life of Oscar or on the road with the Rare Disease team which led to double-page exposure.

Outcome

In less than six weeks Grapevine secured over R7 million of national media coverage and EURORDIS acknowledged that South Africa had achieved the most coverage across all markets for this international campaign.

The latent result, Grapevine has been appointed by the NPO to further promote their activities and educate the public about rare diseases, and the support that is available to patients and their respective families.