

## RARE DISORDERS

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Rare disorders may affect only a small percentage of the population, but these disorders are often serious, life-threatening and a detriment to patients' quality of life. The challenges of living with a rare disorder are often magnified for patients and their caregivers due to a lack of awareness among healthcare providers and the public. On behalf of our clients, MCS collaborates with these unique patient communities to develop innovative media campaigns and educational initiatives that reach a variety of professional and consumer audiences.

### Products/ Clients:

- **Arcalyst<sup>®</sup>** (*Regeneron*)
- **Berineri<sup>®</sup>** (*CSL Behring*)
- **Corifact<sup>™</sup>** (*CSL Behring*)
- **RiaSTAP<sup>™</sup>** (*CSL Behring*)
- **Somavert<sup>®</sup>** (*Pharmacia, now Pfizer, Inc.*)
- **Vivaglobin<sup>®</sup>** (*CSL Behring*)
- **Zemaira<sup>®</sup>** (*CSL Behring*)

**Conditions:** Acromegaly, alpha-1 deficiency, Cryopyrin-Associated Periodic Syndromes (CAPS), factor XIII deficiency, fibrinogen deficiency, hereditary angioedema, primary immunodeficiency

### Creativity and Service:

- Collaborated with leading KOL to develop CAPS awareness website aimed at educating both patients and physicians about the diseases.
- Established relationship between Regeneron and two key third-party organizations -- NORD (National Organization for Rare Disorders) and the NOMID Alliance -- to ensure inclusion of CAPS information on prominent health websites.
- Worked with the Pituitary Network Association, a national patient advocacy group, on a multi-faceted media campaign to heighten the profile of pituitary disorders.
- Coordinated a satellite media tour with iconic Hollywood movie "villain" and acromegaly patient Richard Kiel (best known as "Jaws" in the James Bond films) to raise awareness of this underdiagnosed disease and its complex symptoms. Tour generated coverage in six of the top 25 markets with a combined audience reach of nearly 1.5 million viewers.

### Results:

- Secured publication of bylined article, in collaboration with a leading physician expert, on congenital fibrinogen deficiency in *Pharmacy Practice News*.
- Increased patient recruitment at 16 investigational sites nationwide through a grassroots media outreach campaign on behalf of CSL Behring's hereditary angioedema treatment, Berineri.
- Generated key media placements in outlets such as *American Medical News* by leveraging results from a study conducted by the Respiratory & Allergic Disease Foundation, which highlighted the common misdiagnosis of Alpha-1 Antitrypsin Deficiency as COPD.
- Secured a front page article on the prevalence of pituitary tumors in the *Globe and Mail*, the largest national newspaper in Canada.