



Mark
Krueger & Associates, Inc.

MK&A News

Winter 2011

Welcome to the first edition of "MK&A News," a quarterly e-newsletter to familiarize you with our firm's offerings and highlight developments in constituency relations of interest to the pharmaceutical, biotechnology, and medical device and diagnostic companies. We're proud to focus our inaugural issue on rare diseases, spotlighting Rare Disease Day. This global event is an excellent example of the power of the patient voice to affect change. The firm is also delighted to introduce its newest vice president, Ellen Coleman, MSSA. You can expect future issues to include: patient and industry leader perspectives, case studies of effective partnerships, tips for working with patient, consumer and professional groups and interviews with leading thinkers and doers.

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Uniting Rare Disease Patients Worldwide



Rare Disease Day

February 28, 2011 will mark the fourth World Rare Disease Day coordinated by the European Organisation for Rare Diseases (EURORDIS) and organized with rare disease alliances in more than 40 countries worldwide. Hundreds of patient organizations will host education and awareness-raising activities to focus a spotlight on rare diseases as an important global public health concern.

This year's theme "Rare but Equal" emphasizes the fact that people living with rare diseases should be entitled to the same access and quality of care as any other patients. Peter Saltonstall, CEO of the US-based National Organization for Rare Disorders (NORD), describes the challenges faced by patients and their families as: "delayed diagnosis, few treatment options, and difficulty finding medical experts." He

About MK&A

MK&A is a health care constituency relations firm that focuses on helping pharmaceutical, biotechnology and medical device and diagnostic companies foster relationships with patient, consumer, and professional organizations that speed the development, approval, and appropriate use of innovative medical products and services so that all patients have access to the best available treatment options.

Core Services

- Research and business intelligence
- Strategy
- Patient group relations
- Professional group relations
- Policy influencer outreach

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also notes that many rare diseases have no treatment options, and those that do, may not be covered by insurance.

Pharmaceutical and biotech companies are frequently stymied by lengthy and expensive clinical study processes involving small number of patients. CEO of EURORDIS Yann Le Cam is seeking innovative solutions and "calling for a new paradigm for drug development, approval and access." He suggests that key concepts include: "early dialogue between relevant stakeholders; rolling-on pro-active and flexible scientific advice, as well as protocol assistance; knowledge-based value of a drug in the therapeutic strategy of a given rare condition; and value-based pricing schemes."

For information about Rare Disease Day activities in the US: www.rarediseaseday.us

For information about Rare Disease Day activities around the world: www.rarediseaseday.org

Putting Pulmonary Hypertension in the Spotlight

As part of Rare Disease Day 2011, the Pulmonary Hypertension Association Europe (PHA Europe) and its national affiliates will launch a multi-media campaign to increase awareness of pulmonary hypertension (PH), with a particular focus on pulmonary arterial hypertension (PAH).



The 'Breathtaking' campaign features community-based educational activities in more than 10 countries, demonstrating how patients' lives are impacted and highlighting symptoms such as unexpected breathlessness, weakness and fatigue.

Designed to increase awareness and educate the public about the everyday challenges people living with PH face, such as walking and climbing stairs and the disruption to patients' quality of life. An online component includes content on the website www.phaeurope.org and social media engagement through Facebook where you can send blue kisses to Facebook friends via the [Breathtaking Facebook application](#).

The "Breathtaking" campaign is sponsored by Bayer Healthcare and is linked to the activities of EURORDIS and NORD and will include international launch events in Brussels and Vienna on Rare Disease Day on February 28.

MK&A provides advocacy relations counsel to Bayer Healthcare.

Staff Spotlight: Ellen Coleman

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Join Our Mailing List!

Ellen Coleman, MSSA has joined the firm as vice president, bringing impressive experience in leadership positions at EmergingMed, CancerCare, and Johnson & Johnson. She has advocated for people with cancer, infectious diseases, HIV/AIDS and critical care patients. A medical social worker by training, Ms. Coleman also spent 10 years practicing, mostly at the Cleveland Clinic Foundation. She has published and presented frequently on the psychosocial aspects of life-threatening illnesses and has received numerous honors for her work.



You can contact Ellen by phone directly at +1 212 620 2751 or by e-mail at ecoleman@kruegerandassociates.com.

In Closing...

MK&A has long been a leader in the rare disease community and we have used our knowledge and expertise in various ways to help our clients reach their goals. Among the firm's notable achievements are assisting in the return of thalidomide to legitimate medical use; the launch of a new treatment for urea cycling disorder, a rare disease; structuring more than five pre-approval drug access programs for promising orphan disease experimental agents; and supporting appropriate access and reimbursement for new and novel treatments for rare disease patients.

Let us know how we can assist your company in reaching its advocacy relations goals by calling us at + 1 212 620 2770 or e-mail us at mkrueger@kruegerandassociates.com.

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