## **NEWS RELEASE**

## **Today is Acromegaly Awareness Day**

NEWS PROVIDED BY Canadian Pituitary Patient Network Nov. 1, 2017, 7:00 ET

## Speak to Canadians leading awareness for rare pituitary condition that causes excess growth

Vancouver, British Columbia, Nov. 1, 2017 – Acromegaly is a rare disease in adults which is difficult to diagnose due to its slow progression and varied symptoms. Currently, there are at least 2,000 Canadians affected by acromegaly with still more undiagnosed. In fact, while diagnosed in 3-4 in one million persons per year, it is present in 60 in one million persons.<sup>1</sup>

"I had no idea what acromegaly was, or ever associated the symptoms with the condition. I only recognize them now, retrospectively. It started almost 40 years ago with the physical changes such as my hands and feet growing and with me becoming larger and taller. Later, it became more serious with hip pain so strong I was unable to walk, debilitating headaches and blurred vision. It wasn't until 2009, almost 30 years later, that I was diagnosed with acromegaly," says Brent Baker, Vice-President of the Canadian Pituitary Patient Network and past President of the Alberta Pituitary Patient Society.

Most commonly caused by a benign pituitary tumour, acromegaly leads to abnormal growth and can include enlargement of the hands, feet and facial features, increased spacing of teeth, headaches, problems with vision. Many other complications afflict acromegaly patients including arthritis, diabetes, sleep apnea, hypertension, colonic polyps, carpal tunnel and enlarged internal organs such as the heart. Acromegaly also has hidden family, work, social and psychological impacts, often causing those affected to suffer in silence and isolation.<sup>1</sup>

In spite of their challenges, acromegaly patients such as Peggy MacDonald, Founder of the Atlantic Acromegaly Support Society, continue to persevere. Peggy is an active volunteer in her community. She and her husband are foster parents, and have looked after more than 60 kids over the past 20 years. "The need for patient advocacy and for patients to see that they're not alone are just some of the reasons why I continue to work with the Society," she explains.

Deanna Badiuk-Black, President and Founder of the Vancouver Acromegaly Support Group, describes the ultimate goal as "bringing awareness and knowledge to the general public about acromegaly in hopes that those with this condition can be diagnosed as soon as possible and start educating themselves and receiving the support they need, but most importantly, not feel alone and lost."

Patient support is provided via regional associations across the country: <u>Canadian Pituitary Patient</u> <u>Network</u>, <u>Vancouver Acromegaly Support Group</u>, <u>Alberta Pituitary Patient Society</u> and the <u>Atlantic</u> <u>Acromegaly Support Society</u>.

Brent, Deanna and Peggy are available for interviews and can speak to how acromegaly has impacted their lives and what they are doing to help raise the profile of acromegaly in Canada.

For further information or to arrange interviews, please contact: Katia Kononova, Edelman, 514-315-1975, <u>katia.kononova@edelman.com</u>

<sup>&</sup>lt;sup>1</sup> National Institute of Diabetes and Digestive and Kidney Diseases. Endocrine Diseases. Acromegaly. Available at: <u>https://www.niddk.nih.gov/health-information/endocrine-diseases/acromegaly</u> Accessed October 2017.