For nearly two decades, Novartis has been committed to advancing the care for patients with acromegaly—a rare, chronic endocrine disorder caused by excess growth hormone (GH), which can result in enlarged hands, feet and internal organs. During this time, there has been significant progress in understanding acromegaly, and dedicated researchers, healthcare professionals and patient advocates have helped to change the lives of many patients with the disease.

We are proud to be part of this community and share the goal of improving the lives of people living with acromegaly. In this spirit, we asked acromegaly patient advocates from around the world to offer their thoughts on advancements in this disorder over the years, and have included highlights of their submissions here.

We look forward to continued progress and partnership with the acromegaly community as we strive toward our collective goal of further enhancing outcomes for people diagnosed with this condition.

Acromegaly Perspectives

Rare diseases? They are not rare any longer when they happen to you or someone you love. One of the first things we do today when we receive a diagnosis is to look for information on the Web. This was not possible two decades ago. Today, the support is within the touch of a keypad or a phone call away. Patients are not alone anymore and have the option to engage in research for these diseases, enabling a better quality of life and most of all, hope. Access to novel drugs is still a challenge in Brazil, but with joint efforts by patients and associations, there is light at the end of the tunnel. Life has changed for the better.

Espaco de Vida, Brazil

Over the last seven years in Bulgaria, we did a lot of events and programs, which educated patients about how to follow their treatment according to their doctors’ instructions and thus improved treatment compliance. The use of medicines with different doses enabled doctors to use different approaches to treatment in order to achieve better results.

Association of People Suffering from Acromegaly in Bulgaria, Bulgaria

In Chile, there have been fundamental changes in public health policies—a step forward from when a few patients were treated the right way; it was a privilege for those few. We are still working to improve access to new medicines and early diagnosis, and we are still working for patients to afford them better treatment options and to improve their quality of life.

APTEH, Chile

The awareness of rare diseases like acromegaly is growing every day in Colombia. There are two associations, in two different cities, which is a great achievement in awareness and support for patients. However, the impact is not yet large scale, due to the challenge these institutions have in achieving sustainability. They need more support for more education, more economic resources and management-leadership tools. People with acromegaly now receive special protection from the government, and the Ten-year Public Plan of Health in Colombia 2012-2021 includes specific actions for this population.

Asociacion Colombiana de Pacientes con Acromegalia (ACPAC), Colombia

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Fundacion Vivir Creciendo, Colombia

Over the last two decades, the most important advancement for acromegaly patients in Japan has been the inclusion of the pituitary diseases in “the intractable disease program,” which is an integrated system of medical research and social welfare. Before then, few patients could afford expensive treatments. Now, any acromegaly patient can now afford treatments. We believe this change contributes to better prognoses and quality of life for the patients.

Kasukai, The Association of Pituitary Patients, Japan

Recently, we have seen three important changes in Russia for acromegaly. First, the choice of pituitary disorder treatment is getting wider; second, our government has formally recognized rare diseases and changed their status enabling them to be included in the national health program, which brings economic benefits to patients and their families; third, a law has been adopted, transferring all IDT (interdisciplinary diagnostic teams) to specialized departments. These changes are very positive!

Velikan (The Russian Pituitary Patient Advocacy), Russia

In Switzerland, we notice the most important advancements—and expect the development of more efficient medications—in the areas of disease management and the patient journey. Regarding disease management, big hospitals with specialized departments for Endocrinology have seen improvements. On the other hand, family doctors working at the front don’t know enough about acromegaly, and so the right diagnosis often comes too late. Regarding the patient journey, Endocrinology Centers have improved strategies for the treatment of pituitary patients, and they engage in research for these diseases.

The Swiss Association for Pituitary Gland Diseases, Switzerland

When we started 24 years ago, we learned that there was not less knowledge about hormonal/pituitary issues than we realize. With the help of physicians and surgeons we mapped out a plan for awareness, knowledge and recovery for the thousands of patients seeking help. We have made large leaps in most areas, but it’s still a long and tedious process to receive an accurate diagnosis from which a treatment plan can be developed.

Pituitary Network Association, USA