

We are endocrinologists specializing in pituitary disease, specifically Acromegaly. As a group, we have extensive experience and expertise in the management of patients with Acromegaly and are involved in related research. Recognizing that patients needs, including updated information, psychological support, and awareness of treatment options are not always adequately addressed in the clinic setting, and through common interests, we have joined forces to establish this support network. Each center will present programs and meetings locally. These will be advertised on the website and in our newsletter.

Visit our website: www.acromegalysupport.org

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This publication is supported by an unrestricted grant from Novartis Pharmaceuticals.

Disclaimer:

The information contained in this newsletter is for educational purposes only. It is not intended to be used to diagnose or to recommend treatment for Acromegaly. A physician consult should be obtained to address any medical concerns and to obtain medical treatment.

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LIVING WITH ACROMEGALY: A Patient's Story

Having been greeted by my GYN of Newport Beach, during my annual physical when asked, "How are you doing?" upon his entrance to the examining room, I responded "Oh Doc, I feel just awful. I don't know what's going on with me. I am so tired from the moment I wake up each morning. I always have a headache, frequently expanding into migraines; the top of my head feels like I have been hit over the head with a frying pan (as if I had had prior experience to base my description on) and my hands and knees are so painful and swollen. Further, my feet feel like I am wearing cement based shoes. They are so tender to the touch.

I feel swollen all over my body. My mother says I am gaining weight. Suddenly, I am taller than my mother and I am giving away my shoes to my sister. I had to cut my wedding ring off my finger. Ok, fine, my husband decided he wasn't "family oriented" and left me. Surely, these symptoms are all about him. I guess life stress has really

gotten a hold of my body. Otherwise, I feel great, I said." "How about you?" I facetiously remarked.

Without missing a beat, my Dr. retorted, "Boy Jill, it sure sounds like rheumatoid arthritis or acromegaly to me. "What's acromegaly?" I asked. Little did I know that question would be answered and revealed to me in every aspect of my adult life from that day forward. I was introduced to an endocrinologist who ordered a full body x-ray. I was not particularly concerned for the results. I naively thought that the results would return

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negative. We don't do tumors in our family. We don't even get sick in our family. My parents were from the Depression Era and raised my two sisters and me with a first generation American fortitude, "there is work to be done and no time to be sick or consider ones self."

I returned for my appointment to hear of my test results. I sat alone, newly divorced (the other thing my family did not do) with a four year old son to raise, blank with anticipation, a numbing of fear or denial weaving a veil of distance between what I had up until then known and what would soon be the road I would travel upon my return home. Spiritually, that has turned out to be an understatement. The endocrinologist came in and said, "Well, I have good news and bad news." "Excuse me," I wanted to shout, "I have already been given my bad news for the year. One shock is all I am good for." Instead, I sat poised, sitting up straight, legs politely crossed at the ankle, hands folded ever so serenely in my lap. Although I was not well versed in "bad news diagnosis etiquette",

MISSION STATEMENT

We are committed to providing a reliable and authoritative comprehensive support network for people living with Acromegaly and their friends and family. Compassion, empathy, knowledge, experience and research is fundamental for treating all patients with dignity and respect. Our aim is to educate patients about their disease and empower them through knowledge and support.

