Amgen has partnered with the American Behçet's Disease Association and the Vasculitis Foundation to spotlight the personal experiences of people impacted by Behçet's Disease. Behçet's Disease is a rare, chronic, inflammatory condition that can affect multiple systems in the body and can manifest itself in a variety of symptoms, including oral ulcers, genital ulcers, ocular disease, skin lesions and joint pain.\(^1\),\(^2\)

In honor of Behçet's Awareness Day, held annually on May 20th, 221 patients and 29 caregivers completed personalized infographics to help the world understand what it is like to live with and care for someone with the disease. Results displayed in this infographic are an aggregate of the findings from this campaign.

**The Patient Experience:**

**There Is No Clear Path to Diagnosis with Behçet’s Disease**

**FOR PATIENTS TO RECEIVE A DIAGNOSIS OF BEHÇET’S DISEASE, IT TOOK**

- between 5–9 years for 22%
- >10 years for 26%

**MOST PATIENTS Visited Multiple Doctors Before Receiving a Correct Diagnosis**

- 74% Visited 4 or more doctors
- 28% Visited 10 or more doctors

**Behçet Disease May Impact Patients’ Lives in a Variety of Ways**

- Participation in daily activities 33%
- Ability to work 16%
- Mental health 13%
- Relationships with family and friends 11%
- Confidence or self-image 10%

**At Times, Living with Behçet’s Disease Can Feel:**

- Overwhelming 29%
- Unpredictable 23%
- Isolating 19%
- Frustrating 17%

Even though living with Behçet’s can be difficult, it has taught patients to be:

- Resilient 33%
- An advocate for themselves 29%
- Strong 19%
- Compassionate 12%

References:


Caregivers, Who Have a First-Hand Look at the Difficulties of Behçet's Disease, Wish They Had Known:

- The severity and fluctuation of patients' symptoms: 28%
- Where to find a specialist: 21%
- The impact on daily lives and mental health: 17%

Caring for Someone with Behçet's Disease Has Its Challenges, But Has Also Taught Caregivers How to Advocate for Their Loved Ones

At times, caring for a loved one can feel:

- Scary: 21%
- Overwhelming: 21%
- Unpredictable: 21%

Caregivers cope with the stress by:

- Frequently communicating with their loved one: 48%
- Eating well and exercising: 24%
- Attending support groups: 14%

In the future:

 Patients hope for increased disease awareness (10%), research (8%) and a cure (50%)
 Caregivers hope for increased awareness (34%), research (24%) and coordination by their loved one's care team (14%)

Create your own infographic at www.mybehcetsjourney.com

This data was collected between May 20, 2020 and July 22, 2020