

# Alpha1 MZ Foundation - Information & Research

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## **News & Research Update**

Aug 17, 2024

Dear Subscribers,

This time, we have a couple of exciting announcements about strengthening the Alpha1 MZ Foundation in our efforts to support the 35 million Alpha1 MZ patients worldwide in their pursuit of proper and effective medical care.

I am pleased to announce that we have strengthened our Alpha1 MZ Foundation team with two persons with strong backgrounds.

The first person is Margaret Miller (ZZ), a well-known name in the Alpha1 world and an active patient advocate. You may already know her as moderator of our Facebook page, and recently, she became an active member of the Global Liver Institute, where she advocates for Alpha1 patients.

The second person is Reinoud Doeschot (MM), who has a strong social security, healthcare, and research background and who held various high-level positions within the Dutch government. Reinoud's wife and children are MZ's

I am also pleased to announce that the Alpha1 MZ Foundation is now a member of C-Path, an independent, nonprofit company established in response to the FDA's Critical Path Initiative. C-Path's mission is to lead collaborations that advance better treatments for diseases like Alpha 1 Patients worldwide. It currently contains about 1,600 scientists and representatives from government and regulatory agencies, academia, patient organizations, disease foundations, and pharmaceutical and biotech companies.

Below you will find Margaret and Reinoud's introduction letter and an overview of C-Path.

## **Margaret Millar**

Hi, I am Margaret Millar. Most Alphas know me already from my presence in various Alpha1-related Facebook groups. I am an Alpha1 ZZ. I live in beautiful Canada and had a double lung transplant. I am an avid Alpha 1 Patient Advocate serving Alphas with a lifetime of familial and community experience. Advocating across the board with the Alpha 1 MZ Foundation, Global Liver Institute, Alpha 1 Advocacy & Action Coalition, and many other patient groups and stakeholders. Keeping up to date with many aspects of advocacy, such as research into symptoms, clinical trials, pathways, and policies, always keeping the best interests of our greater global Alpha 1 family in the forefront. It is my passion, delight, and pleasure to serve our greater Alpha 1 community and be part of the Alpha1 MZ Foundation.

## **Reinoud Doeschot**

Hello everyone,

My name is Reinoud Doeschot, and I'm delighted to join the Board of the Alpha-1 MZ Foundation. My personal journey with Alpha-1 began when several family members received their diagnosis.

Initially, my focus was on reimbursement options for augmentation therapy due to my previous work with the National Care Institute.

As I delved deeper into Alpha-1, I discovered a significant lack of awareness and understanding surrounding this condition. The fact that so many people remain undiagnosed or receive a late diagnosis, coupled with the realization of its widespread prevalence and the multifaceted role of antitrypsin in the body, sparked my interest in the relationship between Alpha-1 and autoimmune diseases.

Throughout my career, I have had the privilege of contributing to the fields of social security and healthcare in various capacities. I have authored several books on these topics and served as the publisher of the Pharmaco-therapeutic Compass (Farmacotherapeutisch Kompas) in the Netherlands. My professional journey began as a university researcher, followed by various research leadership positions at the Ministry of Social Affairs and the National Care Institute. Additionally, I have actively participated in board functions, including serving as a trustee of the Lansbury House Trust Fund. I am excited to be a part of the Alpha-1 MZ Foundation Board. I firmly believe that this organization is a vital platform for advancing Alpha-1 research, increasing awareness, and ultimately improving the lives of patients.

### **About Critical Path Institute**

Critical Path Institute (C-Path) is an independent nonprofit established in 2005 as a public-private partnership in response to the FDA's Critical Path Initiative. C-Path's mission is to lead collaborations that advance better treatments for people worldwide. Globally recognized as a pioneer in accelerating drug development, C-Path has established numerous international consortia, programs, and initiatives that currently include more than 1,600 scientists and representatives from government and regulatory agencies, academia, patient organizations, disease foundations, and pharmaceutical and biotech companies. With dedicated team members located throughout the world, C-Path's global headquarters is in Tucson, Arizona, and C-Path's Europe subsidiary is headquartered in Amsterdam, Netherlands. For more information, visit [c-path.org](http://c-path.org).

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**And, like always, enjoy the ride !!**

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