

Letter

*You are not alone*

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# *Inscription*

Letter 3 p.

Acknowledgements 6 p.

# *Preface*

In this letter you will find various messages that member and non-members of the NOI CI SIAMO committee would like to give to a person with FOP or their family.

Message from  
*Roger René Müller*

★ To you, who face each day with courage. Know that you are never alone, we are with you with your rare disease, every step of the way. From each challenge comes a strength we do not know, and together we can light the path. With all our love. ❤★

Message from  
*Johannes Roth*

Always remember, it doesn't matter whether you have an ultrarare disease or a disease that affects a lot of people, you deserve that people including doctors care about you. Your life is unique and it matters. There is always a way to make your life a beautiful journey and it is best done together with a team of friends, family and medical professionals.

Message from  
*Patricia Delai*

Is it hard to do something simple? Take your time...no one wants you to rush. Can't get it done? It's frustrating, we know... but we'll find a way to get you to do it again. We are working, we are thinking! And there's only one set of things we want from you in return... : keep smiling, keep believing, keep the spirit happy. We are here for you!

Message from  
*Gianpiero Bianchi*

FOP is not fought alone. When the NOI CI SIAMO Association was founded, there were no solutions. Being together was the only way out. We did it by hugging, crying, singing, dancing! Yes, we also managed to regain the joy of life... to create a strong and winning spirit! Today the cures are there, the hopes are increasing day by day. However, the road is still long and difficult. There are still obstacles to overcome but together we will make it! Come with us, walk with us, win with us!

*Message from* **Myriam Sargent**

You don't have to look at the whole staircase.

One step at a time, one thought at a time, one task at a time, one day at a time.

Because you are not alone climbing those steps 

*Message from* **Valeria Pironaci**

Hi, how are you doing?

I hope well and if not, don't worry, I am there, we are there. We are at work for you, we will support you with all our strength.

When I was told about people with FOP the first thing I was told is that you have an extraordinary joy of life, an uncommon strength. But not every day is like that, we all have our bad moments, perfectly normal. Always remember: you are not alone in feeling this. If you want and when you want we are there.

*Message from* **Gaia Termini**

To people with FOP I would like to tell them to surround themselves with people who will turn "you can't" into "let's make it possible," to live their lives to the fullest without getting stuck and without depriving the world of the people you are and what you have to offer.

*Message from*  
**Beatrice Roduner**

Dearest,

I want to tell you from the bottom of my heart how much I admire your daily struggle. It is impressive to see how you show strength and courage despite the challenges your rare disease brings. Your way of coping with various difficulties, whether in daily life, at work or in your social life, truly deserves recognition.

I can only imagine how much you face every day, and yet you radiate extraordinary positivity. You are a true example to many and prove that the joy of living is possible even in difficult times.

Please know that I am by your side and my support is guaranteed. If you need someone to talk to, help or just company, I am here for you. You are not alone in this battle.

With all my support and admiration,

Beatrice Roduner

*Message from*  
**Rossella Bianchi**

Person with FOP on the road of life I met you and felt within me your suffering but also your strength of spirit.

Your dream that the body can fly again like your thoughts is also mine.

A dream that thanks to medical research but above all to love and solidarity will come true.

I am by your side.

Rossella

A hug

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German and English Translation  
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Would you also like to leave a letter for person with FOP or families?  
Send an email to: [media@noicisiamo.ch](mailto:media@noicisiamo.ch)