



SALA STAMPA DELLA SANTA SEDE **BOLLETTINO**

HOLY SEE PRESS OFFICE BUREAU DE PRESSE DU SAINT-SIÈGE PRESSEAMT DES HEILIGEN STUHL
OFICINA DE PRENSA DE LA SANTA SEDE SALA DE IMPRENSA DA SANTA SÉ
BIURO PRASOWE STOLICY APOSTOLSKIEJ دار الصحافة التابعة للكرسي الرسولي

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Audience with the Members of the “A Rare Life” Association

At midday today, in the Clementine Hall of the Vatican Apostolic Palace, the Holy Father Francis received in audience the members of the “A Rare Life” Association, at the end of the nine stages of the “Rare Words Run”, which started out on 21 April from Monticelli Brusati, Brescia, Italy, and arrived today in Rome, and is intended to give voice symbolically to those who are affected by *Allan Herndon Dudley Syndrome* (AHDS-MCT8) and those who support the Association, engaged in supporting scientific research and healthcare in relation to rare diseases.

The following is the Pope’s greeting to those present:

Greeting of the Holy Father

Dear friends,

Thank you for coming! Thank you to the president, Davide’s father, who presented your story, and also this initiative which has brought you here to Rome in the sign of hope.

I am always happy to meet associations for research and solidarity in relation to rare diseases. Certainly, there is pain for the suffering and hardships, but I am always struck by – and admire – the will of families to join together to face this situation and to do something to improve it. You, Giorgio and Rosita, together with Davide, your son, felt within you the impetus to do something for him and for people afflicted by a very rare disease, and for their families.

The name you have given your association – “A Rare Life” – is revealing, because it expresses Davide’s situation, but also yours with him, in a positive way, not negative. The negative exists, we know, it is daily life. But this name shows that you know how to look to the positive: that every human life is unique, and while the disease is rare or extremely rare, it is life that is so first and foremost.

This positive outlook is a typical “miracle” of love. And it is love that does this: it knows how to see the good even in a negative situation, it knows how to safeguard the little flame in the midst of a dark night.

And love works another miracle: it helps us remain open to others, capable of sharing, of being in solidarity even when one is suffering from a disease or difficult condition, that can be wearing in daily life.

I believe that this same attitude, for which I thank God, gave rise to the 700 kilometre race, which started ten days ago from your home and has arrived today in Rome. A race for life and for hope. I congratulate all those who have given life to this “Rare Words Run”, and those who have collaborated.

I thank you again. I will pray for you and for your association, And you too, please, pray for me. Thank you.
