LA VOCE DEI MALATI RARI IN ITALIA







#1 Every approach is different

- The Colosseum lightening costs were covered by the body providing the normal lightening. There is a Committee that decides on the requests submitted.
- The Leaning Tower lightening was funded by the EU Commission following the request of ReConnect ERN(Leader is in Pisa)
- For the other monuments the cost was covered by Municipalities









#2 Work with patient organisations

- Start the whole process as soon as possible, illuminating a building can take quite a long time depending on the number of bodies involved
- ➤ Identify the bodies that "own" the building/monument, but also who is responsible for the electricity and lightening costs
- Coordinate with other patient organisations to illuminate landmarks and monuments in different cities.
- Prepare a communication strategy on social media. This will strengthen the thread of illuminated national monuments and buildings.









#3 We can create an impact

- > Every single picture is fantastic, but organising a professional to take some nice pictures is an added value
- Engage family, friends and your community to share them on their social media profiles
- Remember to send them to EURORDIS!!!!

rarediseaseday.org







Thank you for your attention!

Let's have a great and bright Rare Disease Day 2021