



Report of the results obtained from the Jane's Walk questionnaire

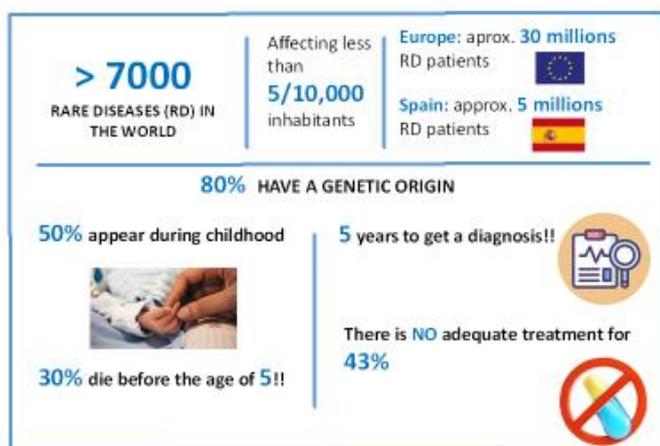
Malaga May 8, 2021

More than 50 people from very diverse locations have answered to this questionnaire. Although most of them are from the city of Malaga or other cities in the province, we have also received responses from other zones of Andalusia (Cádiz, Jaén, Seville, Granada) and other Spanish regions (Ibiza, Logroño, Madrid), and even from Texas (USA).

A 40-42% of the responses came from people affected by a rare disease (RD) or a relative/friend of the affected person. Only 7% of those surveyed indicate that the RD patients they know never like to walk. The vast majority find it pleasant to walk comfortably at some point, since it helps them to integrate themselves in the community and to fight against usual associated problems, such as depression, stress, social isolation, sedentary lifestyle or other physiological problems. However, it is important that the patient is not rejected in public. In general, relaxed walks under comfortable conditions are considered very healthy by more than 97% of those surveyed. Therefore, we believe that we should ensure that these optimal conditions exist. For this reason, in the following paragraphs, we will try to expose those response-deduced factors that would improve the wellbeing and the almost "therapeutic" utility of the walks of people suffering from ERs, with the aim of achieving a city as pleasant as possible for everyone, including the 8% of the population that these patients represent.



RARE DISEASES IN NUMBERS



An important percentage (> 70%) affirms that "sometimes" affected people can feel integrated into the life of the city. Only a 25% believes that those who suffer RDs can never feel integrated. The most general opinion is that the degree of difficulty is highly dependent on the type of symptoms that each patient presents. Some

respondents state that sometimes there are situations of rejection and social marginalization, due to the ignorance about rare diseases, disregard and/or lack of empathy of some citizens. These situations use to be very painful for patients and their caregivers. They even denounce institutional limitations of attention to their needs (negligence or slowness in dealing with claims of their rights, few integration activities, as well as no action in benefit of the mobility of the blind or wheelchair-dependent people). Several surveyed people underline the fact that variability between humans is inherent in biology, and that all humans have particular needs at some point in life; so that all citizens (whether they are RD patients or not) have the right that their city is designed in order to they can enjoy it as much as possible and for being a space that generates well-being. The Jane´s walk team at Malaga agrees with this idea.



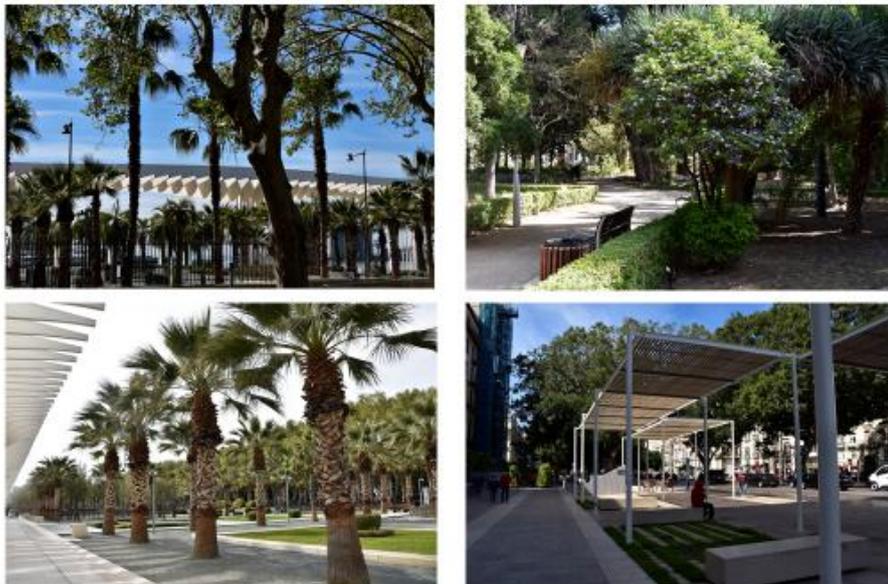
Among what they miss in their neighborhood/city are:

- The possibility of having support staff for various day-to-day activities.
- Appropriate spaces to wait, rest or have a little privacy to solve hygiene problems or others that may arise.
- The provision of shady areas and paths (especially for patients who suffer damage from sunlight radiation (eg: xeroderma pigmentosum, photophobia, albinism, some allergies, among others). This problem can be really important and deserves special care in sunny cities like Malaga.
- Emphasis is placed on the need to increase the degree of inclusive training, respect, empathy and citizen acceptance, regarding the needs of ER patients.
- It is remarked the benefit of associations that can join forces to combat adaptation and acceptance problems, as well as specialized care centers.
- People demand elimination of architectural barriers, and more improvements in parks, gardens, walks, width of sidewalks, and urban furniture in good conditions. There are very different responses among those surveyed, probably due to architectural and service differences among cities and neighborhoods. The answers pose a warning about the existence of deterioration of the surfaces on which they walk, which are very dangerous for those patients who have motor or vision deficiencies.

Unfortunately, there are almost 75% who think that the relationship and the support they receive from their neighbors are not adequate, or they are only occasionally. There are those who feel incomprehension, isolation and rejection. Some of the testimonies given in response have been really harsh, including complaints from neighbors for not understanding the casuistry of some diseases or lacking empathy and generosity. However, there is 25% who always feel supported by their neighbors.

Respondents state that the autonomy of RD patients in general could be improved through different actions such as:

- Have wide and/or pedestrian streets, as well as more open and clean environments.
- Actions that facilitate transport and minimize the inconveniences associated with. For example, the possibility of accessing a disabled parking pass for the family of the affected person. A deficit is also detected in the number of public transport units (buses, taxis) adapted for people with reduced mobility. An increase in the number of public transport stops is suggested to ease the travel of patients who require a wheelchair.
- Institutional organization of more citizen awareness activities to respect and care for those affected.
- Acceptance and normalization of these patients is essential.



Only 27% of respondents think that the amplitude of the spaces and the lighting and ventilation conditions of the public spaces where they operate on a day-to-day basis are always sufficiently appropriate. 67.3% think that only sometimes. Answers indicate that people who live in low houses, and areas with large landscaped spaces, well lit and with shaded spaces find it easier to walk.

The vast majority (86.5%) think that only sometimes it is easy to access community services in the city compared to 9.6% who think that they always get it. Probably, it depends on the area of the city and the economic level or social visibility of each area. In general, it is thought that there are still pending improvements in some areas of the city.

They testify that it is when you have pathophysiological limitations that difficulties are perceived more clearly. Among the most common, steps, poorly closed manholes, faults in the pavement, non-existent or too steep ramps, sidewalks that are too narrow or unduly invaded by bar/restaurant terraces, narrow or non-working elevators. Deficiencies have also been revealed in terms of the number, accessibility and degree of

hygiene and maintenance of public toilets. In fact, 52% think that there is not enough space available to solve the difficulties that may arise regarding hygiene. This public service, essential in a city, usually depends on the goodwill of private businesses such as bars or restaurants. Similar data have been obtained in response to the question about street furniture. An 80% thinks that it is only sometimes comfortable and an 12% answers that it never is. Among the deficiencies detected are that some need to be more accessible, for example, that there are some that are shorter and adapted to children with movement difficulties. Maintenance tasks should be reinforced on a regular basis. and not just on special occasions.

Almost 40% think that it is very difficult to find nearby spaces where to solve the difficulties that may arise related to disruptive situations (for example, an epileptic seizure, a blackout, an anxiety attack, etc.). Some mention that they only have bus stops as a refuge in an emergency situation. Others suggest more frequency of assistive devices in common places (i.e.: defibrillators, drinking fountains, etc.). However, 55.6% of those surveyed answered that they sometimes find these refuge spaces in their area. Problems are also exposed in terms of the lack of speed with which the urgent problems of these patients are attended to, and the lack of social awareness about these problems.

In addition to those mentioned above, among the most difficult situations they find when walking around the city are: the frequency of slippery surfaces, narrow or dirty sidewalks due to animal detritus or with the pavement surface interrupted by unevenness, damage in the pavement, irregular sewers, trees or traffic signs that impede the walk of blind people or people with motor difficulties, badly parked cars invading the sidewalk, excessive pubs/restaurant having external terraces, accumulated garbage, lack of public services. Other important difficulties are: High-traffic areas with crowds of people, excessive environmental noise and the lack of large parks and gardens without shaded areas, that are not well lit at night and that lack attention services for indisposed citizen.

Human beings can also provide difficulties due to lack of empathy and solidarity of some ignorant, badly educated or simply impertinent fellow citizens. Therefore, greater efforts are demanded from the administration to increase the degree of dissemination, research and clinical specialists of ERs in the city, as well as the convenience of fostering and supporting associations of affected people, mentoring programs and volunteering. They believe that it is essential to improve the health care of these patients in many aspects, such as the time spent in patient care and the efficiency of health actions; as well as a solution for problems that arise in the transition to adult life, when their problems are no longer unified in the pediatric services. It insists on the need to support research and training of health professionals specialized in RDs and personalized medicine. They also demand actions that promote and coordinate jobs for these patients adapted to their circumstances.

The Jane's Walk Málaga 2021 team sincerely appreciates generosity of all those who have answered our questionnaire. We remain at your disposal through janeswalkmalaga@gmail.com.

