



Manifesto of the rights and duties of persons with respiratory allergies

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Received: December 3, 2024 **Accepted:** December 27, 2024 **Published:** February 7, 2025

Cite this article: Di Gioacchino M, Patella V, Bonini S, Del Giacco S, Canonica GW. Manifesto of the rights and duties of persons with respiratory allergies. *Explor Asthma Allergy*. 2025;3:100972. <https://doi.org/10.37349/ea.2025.100972>

Introduction

Respiratory allergies represent a global problem and entail a significant social and economic burden to national health systems. According to the World Health Organization and data in the literature, approximately 350 million people worldwide suffer from diseases related to respiratory allergies, such as rhinitis and bronchial asthma. The aforementioned diseases are chronic and heavily influence the quality of life of patients with major social, economic and clinical implications. The appearance and recurrence of symptoms (especially cough and breathing difficulty) require a demanding management, with regular, urgent specialist visits and even hospitalizations for the management of the most severe cases. According to the US Centers for Disease Control and Prevention, children with respiratory allergies miss twice as many days of school as their peers. In Italy, approximately 10% of children under 14 suffer from asthma and 80% of them are allergic. Respiratory allergies are the cause of asthma in 80% of cases and it is therefore essential to act on their prevention. An essential element in preventing respiratory diseases is represented by the observation of the origin in the first years of life of numerous chronic lung diseases in adults, including asthma, which unfortunately record still worrying morbidity and mortality rates. It has been demonstrated that the increase in the level of hygiene and exposure to pollutants, typical of the most advanced societies in the world, influences the immune response by promoting allergic sensitization. Furthermore, in addition to the environmental risk factors, individual, genetic, family-related, behavioral and lifestyle-related risk factors should also be taken into consideration, as they have a major impact on many pathologies including allergic rhinitis and asthma, especially in childhood. The Italian Study on Asthma in Young Adults (Isaya), a multicenter survey carried out between 1998 and 2000 in nine Italian cities on 3,000 people between the ages of 20 and 44, highlighted the correlation of the frequency and severity of respiratory allergies with high levels of pollution. In Italy, it is estimated that around 15–20 percent of the Italian population suffers from allergies in general, a growing phenomenon especially among young people, and around ten million people suffer from respiratory allergies (essentially pollen, mould, mites and pets). The direct costs of asthma, derived from the use of drugs and health services, represent approximately 1–2% of the health expenditure, while the indirect costs (for work/school absenteeism and



reduction of parents' working days due to childcare), constitute over 50% of the overall costs, reaching an impact, in economic terms, greater than diseases such as tuberculosis and HIV infection combined.

Faced with a significant epidemiological situation, allergy care appears to be significantly scaled down in Italy, both at national and regional levels. Allergic diseases are often not fully considered in their clinical severity and implications on the quality of life of people, both in developmental age and in adulthood. Equal access to the use of the most advanced therapies for the treatment of respiratory allergies is not always guaranteed, including desensitization therapies and NPP ("Named Patient Products") regulated by art. 5 of Law no. 94/1998, in line with the principles of therapeutic appropriateness, sustainability for the national health system and equity of access to care in all regions.

This Manifesto is an incentive to protect the rights and access to care for persons with respiratory allergies and to strengthen and rationalize assistance by promoting the growth of large specialist facilities in constant and dynamic connection with the territory.

Methodological Note

Public health manifestos are essential tools for communicating important information on disease prevention, health promotion and the management of health emergencies.

The following operational path was followed:

1. The first step was to draft a basic text based on international benchmarking on the right to health, on insights provided by participants in the creation of the manifesto and on desk research and analysis on the topic of respiratory allergies.
2. The second step was to receive a review/integration by patient associations and civic representative organizations.
3. The third step involved the review/integration of the text by the Technical-Scientific Committee.
4. The fourth step was based on the verification by qualified external referees of the elements relating to the right to care and health. The referees' task was to verify that what is mentioned in the manifesto is in line with the principle of the right to health as expressed in institutional documents.
5. The fifth step involved the signing and presentation of the manifesto.

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The Guideline Act regarding the methods of participation in the decision-making processes of the Ministry of Health by side of Associations or Organizations of citizens and patients involved in health issues, the European Charter of Patients' Rights of Cittadinanzattiva APS, promoted by ACN - European network of Cittadinanzattiva, and the Charter of Rights of the Asthmatic and Allergic Citizen of Federasma and Allergie Odv - Italian Patient Federation, are integral parts of this Manifesto.

Section 1: Rights of the person with respiratory allergies

The rights of people with respiratory allergies are the same human and social rights as those without. The rights include, among others, equal access to information, prevention, therapeutic education, treatment of respiratory allergies and diagnosis and treatment of complications. The health service must guarantee the person with respiratory allergies access to appropriate diagnostic and therapeutic methods, uniformly throughout the national territory.

The right of people with respiratory allergies to live a social, educational and working life equal to people without respiratory allergies must be considered as an objective of governmental actions.

Recommendations:

1. State that having respiratory allergies does not preclude the possibility of pursuing (successfully) personal, family, work, sports, school and social goals.
2. Increase awareness of the social impact of respiratory allergies in school, at work, in places where sports are practiced, in health facilities and generally in the whole society to avoid discrimination and personal and professional preclusions.
3. Support the person with respiratory allergies and their family members in overcoming obstacles, prejudices and mistrust using information, training, educational and social tools, together with the empowerment and active participation of institutions, the social-health system, scientific and patient associations, and volunteering and civic organizations of people with respiratory allergies.
4. Ensure that people with respiratory allergies have uniform access to the health service throughout the country, to equitably promote the best quality of care and life, prevention and treatment of complications.
5. Educate social and health workers, teachers and sports instructors, and raise awareness among colleagues on how to prevent, recognize and treat any situations that require urgent intervention.
6. Guarantee in all regions an early diagnosis of respiratory allergies for all subjects at risk.
7. Establish in all regions, a panel of experts that facilitates interaction and exchange between the different subjects and systems (associations, health service, school system, sports and work systems), to handle any requests and applications simply and correctly.

Section 2: Expectations and responsibilities of the person with respiratory allergies and their family members

Patients with respiratory allergies and/or their family members are not always aware of the healthcare path and the goals of long-term pharmacological, nutritional and behavioural treatment, as defined by current guidelines.

The person with respiratory allergies and their family members may mistakenly believe that the situation is "under control" due to the lack of symptoms and therefore decide to suspend the appropriate therapies or modify them inappropriately.

The person with respiratory allergies and their family members must receive correct information on the causes of disease exacerbations, on the risk factors that cause the onset and persistence of respiratory allergies and on the development of complications, so that they are aware of the importance of contrasting them and of leading a healthy lifestyle, in line with their possibilities and needs.

It is therefore necessary to:

1. Educate the person with respiratory allergies and their family members so that they can fulfil their life aspirations.
2. Help families manage respiratory allergies by providing ongoing training and information, tools and services that consider the needs of individuals.
3. Encourage healthcare professionals (specialists, general practitioners, family pediatricians, nurses, psychologists, etc.) to actively listen for an adequate amount of time to the person affected by respiratory allergies and their family members, to understand their needs, aspirations and expectations.
4. Ensure that healthcare professionals explain the therapeutic objectives in detail, always checking for understanding, and recommend personalized and shared treatment plans (prescribed in both written and oral form) for routine treatment and for any emergency situations.
5. Invite all social and health workers to take care of the psychological and social aspects of the person with respiratory allergies and their family members.
6. Contact only specialists in the allergy-immunology sector to obtain the most appropriate therapy based on certified diagnostic tests and scheduled control and follow-up paths.
7. Ask persons with respiratory allergies to respect the correct observance to the prescribed therapies, the methods of monitoring respiratory allergies, the lifestyle indications provided by health workers, with the aim of achieving the planned therapeutic objectives in compliance with the resources made available by the health service.

Section 3: Responsible associationism

The connection exercised by patient associations between the health service, people with respiratory allergies, their families and societies and civic organizations is considered irreplaceable.

It is therefore necessary:

1. Consider associations as a resource and an important component in the strategies for protecting people with respiratory allergies, thus facilitating collaboration between patient associations, citizen organizations, institutions and the scientific community.
2. Provide training carried out by certified public and private bodies and scientific societies in the sector; promote the specific accreditation of patient associations, volunteers and civic organizations of people with respiratory allergies, their families and civic associations in line with national health policies.
3. Consider associations and civic organizations, through people trained for this purpose, of different ethnic and cultural origins, as an active part in information and training courses on the rights and social protection of people with respiratory allergies.
4. Make use of the collaboration of patient associations, volunteers and civic organizations of people with respiratory allergies and their families in respiratory allergy prevention activities.
5. Involve patient associations and citizen-patient organizations in decision-making processes and in defining the political-health agenda on respiratory allergies with the aim of acquiring the position on the measures that are intended to be adopted, so that the issues considered relevant are included in the institutional work agenda.
6. Ensure the participation of patient and citizen associations and organizations in the generation of evidence, through programs, plans, testimonies and experiences to be taken into account in the decision-making process as “patient evidence”.

7. Enhance the activity of associations in the relationships between health professionals and people with respiratory allergies and their families, advising them to participate in association life.
8. Place the associations involved in the definition, monitoring and evaluation of care models that guarantee respect and the centrality of the person with respiratory allergies, with their desires, needs, values and their family and social situation (as well as their clinical needs), at the center of medical choices to overcome any barriers to correct, effective and shared care.

Section 4: Prevention of respiratory allergies

There are effective preventive measures that can be implemented to reduce the onset of respiratory allergies by containing their enormous personal and social impact.

For this purpose, a close collaboration is needed between institutions and patient associations, volunteering and civic organizations of persons with respiratory allergies and their families, and scientific societies.

Systematic and ongoing communication activities can promote the prevention and early diagnosis of respiratory allergies, allowing for timely treatment and the reduction of all its consequences.

It is therefore necessary to:

1. Request local and national institutions to implement effective strategies for the prevention of respiratory allergies.
2. Inform the population that the onset of respiratory allergies can be reduced in people at risk (adults and children) by adopting, where possible, hygiene measures and existing suitable therapeutic strategies aimed at the remission of allergies and the prevention of asthma in children.
3. Convince institutions to allocate adequate resources for the prevention, early diagnosis and therapy of respiratory allergies, and where possible, to avoid or reduce exposure to allergens through continuous and coordinated communication with scientific associations, patient associations, volunteering and civic organizations.
4. Request that the competent bodies authorize only *in vivo* and *in vitro* diagnostic tests, whose methods are supported by adequate scientific evidence.
5. Direct the institutions to implement allergy clinics and specialist reference centers, equally distributed throughout the country to which the patient can turn so as not to fall into the networks of non-specialized personnel.
6. Consider the family, school, work- and recreational places as places for the development of adequate knowledge of respiratory allergies and education for a correct lifestyle.
7. Implement information and health education programs at schools, sports associations, residential centers for the elderly and in general in all living and working environments by involving health institutions, multidisciplinary groups and patient associations and civic organizations to inform how the correct management of prevention measures and adherence to appropriate therapies favor a lifestyle free from constraints and conditioning.

Section 5: Remission and control of respiratory allergies

The person with respiratory allergies must be aware that theirs is a chronic condition, which can either be asymptomatic or with symptoms of varying severity, and must be able to manage their own treatment. A correct management of their respiratory allergies allows them to have a school, work, emotional, sports and relational life like that of a person without respiratory allergies. The therapeutic goal is the remission of respiratory allergies to obtain symptom control or even no symptoms in the absence of a cortisone-based therapy.

It is therefore necessary to:

1. Increase the knowledge of the person with a respiratory allergy and their family members about the appropriate therapies for different clinical conditions, prescribed according to the needs and capabilities of the subject, and their side effects.
2. Ensure qualified specialist care for patients admitted to hospital by also creating Allergology and Clinical Immunology departments as reference centers in territories with adequate population numbers, to also guarantee a correct distribution of resources.
3. Facilitate the bureaucratic process and the prescription methods of drugs and the related administration tools to ensure homogeneous access at the national level to all existing therapies, whether they are symptomatic for the management of acute phases or, even more importantly, therapies that change the natural history of the disease, determining its remission.
4. Promote programs of therapeutic appropriateness to encourage a better implementation of clinical protocols so that the care of the person with respiratory allergies also takes place with a perspective on sustainability of the health service.
5. Inform the person with respiratory allergy and their family members of the possibility of obtaining symptomatic or clinical remission of the disease through a correct treatment, in the absence of a systemic steroid therapy.

Section 6: Commitment to research

Investing in research by universities, health institutions, industry, public bodies and scientific societies is a fundamental factor in understanding, and in consequence preventing and treating, respiratory allergies. It is important that scientific research responds to the real needs of persons with respiratory allergies and in particular in the fields of epidemiology, education and technological innovation.

Thanks to the progress in knowledge of respiratory allergies and their treatment, it will be possible to improve the patient's quality of life and prevent the onset of complications, reducing the costs related to the use of symptomatic drugs.

It is therefore necessary to:

1. Promote the collaboration between research institutions and patient associations, volunteering and civic organizations of people with respiratory allergies and their families to better understand of the real needs of patients with respiratory allergies and consequently direct the available resources.
2. Increase the resources available for investments in scientific research (basic, clinical and epidemiological), and in innovation and training.
3. Promote studies whose objective is the synergy between therapies that influence the natural history of the disease leading to remission and the sustainability of the National Health System.
4. Invest in research and the application of methodologies and means of communication that allow for the effective transmission of rigorous information on scientific innovations on the prevention and management of respiratory allergies and that promote a correct social representation of the person with respiratory allergies.
5. Invest in aerobiological research on the processes of emission and diffusion of allergenic pollens and fungal spores in the atmosphere, in particular, in urban environments also in relation to the effects of climate change, also taking into consideration the biodiversity of plant species.
6. Promote studies on the interaction between allergenic pollens and air pollution, in particular on the increase in the release of antigens with modified allergenicity and on the greater reactivity of the respiratory tract to inhaled pollen allergens, induced by poor air quality in urban environments.

7. Develop a collaborative platform for sharing and integrating data from the National Health System databases on respiratory allergies, so as to generate a corpus of shared and accessible information that, by exploiting technologies such as AI, going beyond descriptive analysis becomes useful and essential for the development of predictive and prescriptive models.
8. Promote the establishment of monitoring registers to have a constantly current and evolving picture of Respiratory Allergies throughout all National territory.

Section 7: Lifelong education of the person with respiratory allergies

Lifelong education of the person with respiratory allergies, their family members and the social-relational context is an indispensable tool for achieving full autonomy in the daily management of respiratory allergies and for preventing and recognizing any complications.

It is important to recognize the central role of educational therapy by providing structured courses.

It is therefore necessary to:

1. Ensure uniformity of access to educational therapy throughout the country.
2. Train healthcare personnel in therapeutic education and volunteering organizations in health education for persons with respiratory allergies and their families, based on their specific clinical and socio-cultural needs.
3. Take advantage of a multidisciplinary group with specific skills (medical, psychological, nursing, social) useful for removing barriers to a proper management of respiratory allergies.
4. Share and agree on, after getting adequate information, the objectives and individualized therapeutic choices in order to facilitate the management of respiratory allergies in daily life.

Section 8: Communication between doctor and patient with respiratory allergies

To achieve an effective management of respiratory allergies, it is essential that the family physician and the multidisciplinary team of reference know not only the biomedical but also the psychological, relational and social aspects of the person, their perceptions, expectations, needs, obstacles and integrate these elements into the care plan.

To this end, a context must be guaranteed in which the person with respiratory allergies can express their opinions and provide the necessary information about their condition.

It is therefore necessary to:

1. Ensure that healthcare professionals establish a real therapeutic alliance with the person with respiratory allergies and their family members that includes active listening, empathetic communication, open dialogue and regular verification not only of the health condition but also of the quality of the service provided.
2. Invite healthcare professionals to support the person with respiratory allergies in acquiring full awareness of their condition and their care.
3. Analyze personal and family habits and dynamics that may represent risky behaviors.
4. Facilitate as much as possible, access and continuity of care even within the specialist centers.
5. Increase the possibilities and frequency of contact with healthcare professionals also by using telematic communication, telemedicine and AI.
6. Facilitate as much as possible, the dialogue between the attending physician/pediatrician and the allergist specialist in order to ensure the application of a common language and strategy.

Section 9: Respiratory allergies in developmental age

Children and adolescents with respiratory allergies have the right to the most appropriate healthcare services in the pediatric field without any distinction of sex, ethnicity, religion and social condition.

It is a duty to take care of children and adolescents with respiratory allergies, paying particular attention to delicate moments such as schooling and the transition to adult care, which will be managed with specific interventions.

It is therefore necessary to:

1. Ensure the best diagnostic process to accurately identify the type of respiratory allergies and the therapeutic strategies suitable for the different clinical conditions.
2. Promote knowledge of the symptoms for the early diagnosis of respiratory allergies to avoid the risks of a late diagnosis.
3. Ensure access to the most appropriate treatments, including the innovative ones and the management of comorbidities.
4. Promote physical activity, including sports, in the best possible conditions and without any type of limitation.
5. Support family members in the management of the child and adolescent with respiratory allergies.
6. Ensure that the child and adolescent have a school, sports, relational and social life that meets their needs and desires, to enjoy a good quality of life.
7. Use a comprehensible language, appropriate for the age, psycho-physical conditions and culture of the child and family members/guardians.
8. Ensure welcoming hospital and outpatient environments, suitable for childhood and adolescence, in which there are dedicated multidisciplinary groups specialized in the treatment of respiratory allergies in this age group and in the assistance of family members/guardians.
9. Guarantee that continuity care of the child and family members/guardians is maintained in Specialized Centers.
10. Ensure the ongoing updating of healthcare personnel to constantly improve their scientific, technical and communication skills.
11. Promote a “network action” in the territory between specialist centers and pediatricians of free choice.
12. Facilitate the transition of the adolescent from the pediatric specialist to the adult specialist in order to guarantee a continuity of care; this process must occur gradually, through the sharing of objectives and therapeutic choices involving their referring doctors (pediatricians of free choice, general practitioners and specialist doctors).

Section 10: Respiratory allergies in the frail elderly

The frail elderly with respiratory allergies have the right to the best health services without any social or cultural discrimination, so that they can continue to have an active role in the community life. It is necessary to take care of the frail elderly with respiratory allergies, paying particular attention to their general health conditions, cognitive conditions, concomitant pathologies and the context in which they live to design personalized and easily applicable therapies, and to educate them about constant home care, if necessary, and the adoption of correct lifestyles.

It is therefore necessary to:

1. Ensure dedicated facilities that consider the specific needs of the frail elderly with respiratory allergies (rooms with dedicated devices, limited waiting times and sufficient visit times for adequate information and training by specifically trained healthcare workers).

2. Use a clear and comprehensible written and oral language that is appropriate for the culture and psycho-physical state of the frail elderly with respiratory allergies and their family members/caregivers.
3. Promote home interventions and the role of local territorial facilities in the management of the frail elderly with respiratory allergies to guarantee continuity of care by a multifunctional and multiprofessional team.
4. Support families/caregivers with adequate training, which prepares them and makes them autonomous in handling the care of the elderly/frail subject with respiratory allergies who are not self-sufficient, and with suitable support to take care of them also from a psycho-emotional perspective.
5. Promote interventions and actions that favor the maintenance of social and friendly life for elderly people with respiratory allergies for the maintenance of an active life, also through the availability of risk-free spaces/places.

Section 11: Immigration and respiratory allergies

A person with respiratory allergies must not be discriminated against on the basis of their language, ethnicity, geographical origin, religion, psycho-physical condition and status.

It is therefore necessary to:

1. Facilitate the access to healthcare services throughout the country for immigrants of all ages who suffer from or are at risk of respiratory allergies, with the use of linguistic mediation services.
2. Adjust where possible, treatment programs for people with respiratory allergies to the customs dictated by cultural and religious traditions if not in conflict with human rights and therapeutic needs.
3. Offer ongoing education courses held by multidisciplinary groups able to communicate multilingually in all living and working environments, supported by staff from patient associations, volunteering and civic organizations.

Section 12: Territory and respiratory allergies

The analysis and continuous monitoring of respiratory allergy data allow us to identify short, medium and long-term strategies that can determine management changes and help spread the culture of prevention as a tool to reduce the incidence of the social and economic costs of respiratory allergies and complications resulting from therapies (i.e., oral steroids). At the same time, monitoring the biological component of airborne particulate matter allows us to produce extremely useful information in the diagnosis, clinic, therapy, research and prevention of respiratory allergic diseases.

Through specific studies carried out at the territorial and national level, it is possible to understand the geographical and cultural characteristics that can determine the onset of respiratory allergies, to increase the socio-political awareness and to improve and standardize the therapy throughout the country to effectively meet the treatment needs.

It is therefore necessary to:

1. Promote the implementation of a National and Regional Plan for respiratory allergies through specific intervention policies, so as to make the therapeutic-care pathway uniform throughout the national territory, in order to avoid or oppose existing discrepancies.
2. Support local and national observatories on respiratory allergies in their data collection and analysis activity, necessary for understanding all the aspects that cause the onset of respiratory allergies and for evaluating the quality of the care provided.

3. Use the available evidence within public awareness campaigns, shared and jointly promoted by institutions, healthcare and associations.
4. Ensure an integrated healthcare organization that contributes to changing lifestyles and the environment in which we live related to the risk of respiratory allergies, as well as provide innovative therapies in an equitable manner.
5. Promote the aerobiological monitoring of allergenic pollens and fungal spores through measurement sites, arranged in a network, spread throughout the national territory.
6. Activate shared protocols for the management of public and school green spaces between/with local authorities, institutions, and associations, in order to adopt management and maintenance measures for green spaces with the aim of reducing/mitigating the presence of invasive and allergenic species, with particular reference to residential areas.

Signatories

- Parliamentary Intergroup on Respiratory Allergies
- Cities+
- Cittadinanzattiva
- Federsanità
- Health City Institute
- Italian Association of Hospital Allergists and Immunologists (AAIITO)
- Italian Society of Allergology, Asthma and Clinical Immunology (SIAAIC)
- Italian Society of Pediatric Allergology and Immunology (SIAIP)
- Italian Society of Pediatric Respiratory Diseases (SIMRI)
- Italian Society of General Medicine (SIMG)
- Italian Society of Pediatrics (SIP)
- “Liberi dall’Asma”, from Allergic, Atopic, Respiratory and Rare Diseases adhering to FederASMA and ALLERGIES Italian Patients Federation Odv Association (ALAMA-APS)
- Planetary Health Inner Circle
- “Respiriamo Insieme” Association

Declarations

Acknowledgments

The authors acknowledge the Presidents (Senator Daniela Sbroliini and Honorable Paolo Ciani) and the Secretary (Dr. Federico Serra) of the Italian Parliamentary Intergroup on Respiratory Allergies for their support in producing the “Manifesto” and the components of the Technical-Scientific Committee and the participants to the “Table on Respiratory Allergies and Urban Health” (Coordinator Prof. Andrea Lenzi) and to the “Social and Communication Table” (Coordinators: Dr. Ketty Vaccaro and Dr. Mariarita Montebelli) of the Intergroup for their criticisms and suggestions. Special thanks to Dr. Lucio Corsaro for its essential help in the production of the Manifesto.

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MDG, VP, SB, SDG, and GWC: Writing—original draft, Writing—review & editing.

Conflicts of interest

Mario Di Gioacchino and Giorgio Walter Canonica are the Editors-in-Chief of Exploration of Asthma & Allergy. Vincenzo Patella is the Editorial Board Member of Exploration of Asthma & Allergy. Sergio Bonini and Stefano Del Giacco declare that they have no conflicts of interest.

Ethical approval

Not applicable.

Consent to participate

Not applicable.

Consent to publication

Not applicable.

Availability of data and materials

Not applicable.

Funding

Not applicable.

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