

5p- Syndrome Association "Chamomile"

Outline of the Association

"Chamomile", an association of the families of children with 5p- Syndrome, was founded in 1995. We marked our 20th anniversary in 2015. There are now 77 families, from all over Japan, in the association. The children of these families include 31 males and 46 females, ranging from infancy to young adults, affected by 5p- syndrome. (as of March 2018)

Our purpose is to provide useful information and mutual support. Our main activities are meetings and newsletters published several times per year.

The meetings have encouraged and supported all of us in thinking about our lives in a positive way through interactions with other families from various locations throughout Japan. We never feel alone with this support system in place. The newsletters provide a platform for sharing our experiences.

Learning about other members' experiences can both guide us and give us hope, especially when we are worried about our children's health, daily routine, school, career, and other aspects of life.

About Our Children

It is necessary for us, the parents of children with 5p- Syndrome, to pay attention to their health conditions such as scoliosis, strabismus, hip dislocation, feeding difficulties, malocclusions, sleep difficulties, gross motor delays, language delays, and poor muscle tone. Some of these children may also have poor respiratory function, heart defects, epilepsy, and seizures. Thus, regularly seeing a doctor for check-ups throughout their lives is recommended.

Our children are curious about everything, especially people. Many children with 5p- Syndrome understand what people say, and have a rich variety of facial expressions. Their friendly and pleasant characteristics make us feel comfortable being with them as well as helping them to enjoy daily life with other people. We hope we can help them further develop their communication skills by using sign language and other communication tools/devices and that they will be able to understand the feelings of others.

Infancy to Pre-school Age: 0 to 6

We take our children to development support centers designed for special needs children to encourage their development employing physical therapy, occupational therapy and speech therapy. We, especially the mothers, initially accompany our children to these centers. We gradually send them alone so that they can become accustomed to both the facilities and group activities, allowing our children to feel comfortable without us. Some also go to nearby kindergartens or nursery schools. It is very important for them to be with kids their own age, to make friends, and to have good times with their peers.

Most of our members enroll in "Chamomile no Kai" before their children start school.

School Age: 6-18

Our children attend either special classes in local schools or special needs schools which provide an education specifically tailored to their physical or intellectual needs. These programs aim to enhance their abilities, allowing them to overcome difficulties and enjoy school life with their friends. During this time in their lives, it is important for our children to acquire the necessary skills for achieving their individual career goals.

Outside of school, they enjoy group activities such as swimming and cooking.

After High School: Age 18 and over

After graduating from high school, most of our children get jobs at welfare facilities for persons with disabilities. There are many types of jobs available; for example, paperwork, packing components, recycling, cleaning, making sweets, making handicrafts, and so on. At their workplaces, they can enjoy exercise, art, and music for relaxation, in addition to performing the various supervised work duties associated with the job.

Since parents cannot look after their children all the time, especially as they become adults, many children with 5p- Syndrome seek an opportunity to live apart from their families. Using the appropriate welfare services, our children strive to live as independently as possible.

Like all parents, we hope that our children can spend their lives happily.

The Worry and the Joy

Like all parents, we worry about our children's medical and living conditions throughout their lives. Of course, we worry more than most because of our children's special needs. They usually require at least some help with their daily routines, so we must maintain close contact with doctors and social workers in order to obtain useful and timely advice.

On the other hand, we are ecstatic when we find our children smiling and having a good time on a daily basis. Had they not been born, we wouldn't have known this true joy and would have had no chance to meet with warm-hearted people like the members of "Chamomile". We would like to provide meaningful advice and support to the parents of newborns with 5p- Syndrome, counseling them not to worry too much and to stay positive. We appreciate doctors conveying the same message to the parents of their 5p- Syndrome patients.

Don't Refer to Our Children as Having "Cat Cry Syndrome"

When one of our members went to the hospital with her child, a hospital employee loudly referred to him as having "Cat Cry Syndrome".

Other people looked at them in a strange way, and the mother was deeply saddened.

Our children are humans just like us, not cats.

We have been asking that the condition affecting our children being called "5p- Syndrome", and not "Cat Cry Syndrome".

This is a message that we intend to continue sending to the public.

Thank you for being interested in the 5p- Syndrome Association.

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<http://5pminusjp-chamomile.org/>