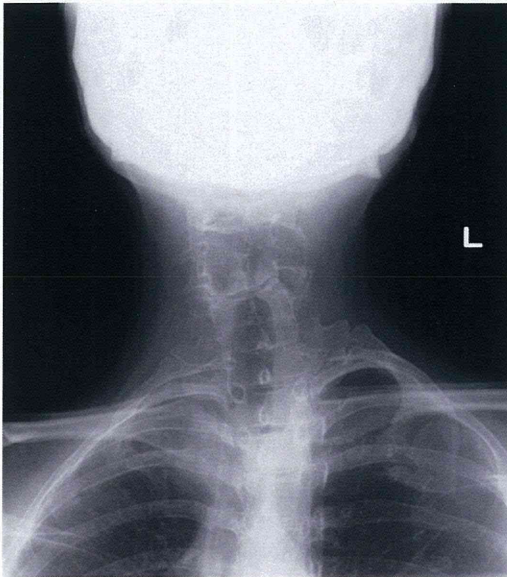


Cervical spine X-ray

The cervical spine can be X-rayed with the patient seated. This requires no movement.



(Fig. 3) Cervical spine AP



(Fig. 4) Lateral

Cervical spine AP (Fig. 3)

If the cervical spine is deformed (Fig. 3), the X-ray can be taken with the patient's head tilted slightly up and down, in turn.

Cervical spine lateral (Fig. 4)

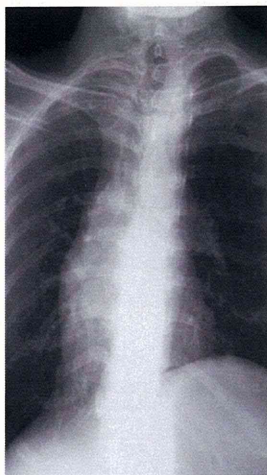
The patient should be seated sideways with the back straightened and the gaze fixed on a single point (Fig.4).

Help should be given to support the head if images with the head bent forwards and backwards are needed.

Thoracic and lumbar spine

For X-rays in the decubitus position, assistance in the form of back support should be given even if the patient can adopt the position on their own. When changing from decubitus to lateral decubitus positions, the patient should be allowed to move on their own, but with staff remaining at their side and providing assistance if necessary. Care also needs to be taken when patients with shoulder malformations adopt the lateral decubitus position, as this is painful.

3. Comments from radiologists



Thoracic spine AP
(Fig. 5)



Thoracic spine lateral
(Fig. 6)



Lumbar spine AP
(Fig. 7)



Lumbar spine lateral
(Fig. 8)

Hip joints AP



This requires inward rotation of both lower limbs, but should not be forced if it is painful. Instead, the patient should be asked to turn the lower limb inwards as far as possible on their own.

(Fig. 9)

Shoulder joints



Shoulder joint true AP (Fig. 10)



Shoulder joint scapular Y (Fig. 11)

Shoulder joint true AP (Fig. 10)

This is taken in the same position that allows visualization of the glenohumeral joint and subacromial joint in normal individuals.

Here, the patient was seated in front of the X-ray plate and the image was taken with the target shoulder at an angle of 30 degrees and the X-ray center line at 20 degrees to the craniocaudal plane.

The subacromial joint could not be captured because of deformation of the scapula.

Shoulder joint scapular Y (Fig. 11)

This is taken with the coronal plane at 70 degrees to the X-ray plate, to separate the scapular body from the ribs.

Here, the image was taken with the X-ray center line at 20 degrees to the craniocaudal plane.

3. Comments from radiologists

Knee joints

AP view

The X-ray is taken with the patient in the supine position, with the knee extended and the patella at the center.

Lateral view

The patient adopts the lateral decubitus position on the side of the lower limb of interest, the pelvis is placed in the true lateral position, and the lower limb of interest is bent at 30 degrees and held in place by supporting the foot with a pillow, rolled up towel, etc. The other lower limb is supported with a support block and the X-ray is taken. (Fig. 12)



(Fig. 12)

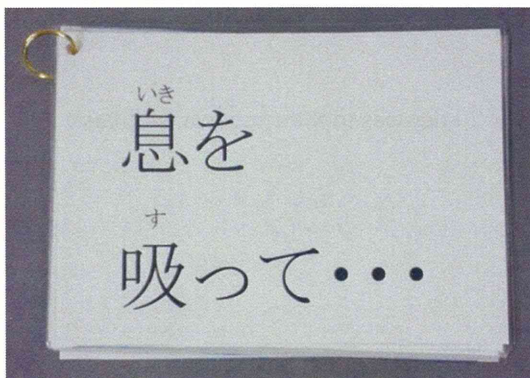


(Fig. 13)

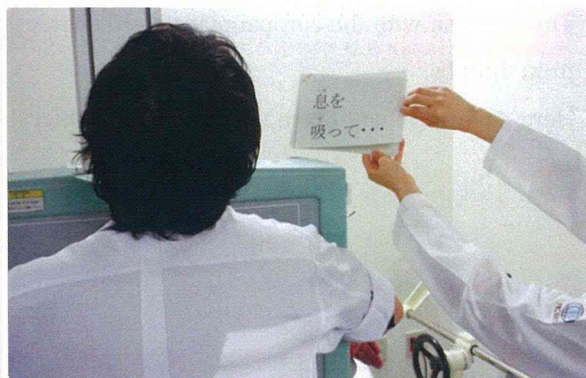
If adopting the lateral decubitus position is difficult, an X-ray can be taken from the side, with the patient in the supine position and the knee of interest supported from below by a support block. (Fig. 13)

Patients with hearing impairments

Instruction cards should be prepared before taking X-rays, and the patient should be asked to follow the instructions shown on each card. (Fig. 14), (Fig. 15)



(Fig. 14)



(Fig. 15)

Q3-2: What points should be considered when receiving thalidomide-impaired patients for X-ray?

- **Patients with upper limb reduction defects have difficulty putting on and taking off examination clothing that needs to be tied at the front, and will therefore need a one-piece examination gown.**
- **Hearing impaired patients will need to be given instructions in writing, or through gestures, lip reading, etc.**

Most hearing-impaired patients use lip-reading, so you should remove your mask and speak slowly.

① What preparations should be made before X-ray?

The radiologist in charge of the X-ray procedure should check the medical questionnaire attached to the patient's medical chart, and should gain an understanding of the patient's degree of impairment and independence, current subjective symptoms, etc. It is also important to closely monitor the patient's physical and mental state throughout the tests by communicating with the patient. This will enable the radiologist to predict any somatic effects and to prevent accidents, such as falls, when taking X-rays.

If further radiology tests are to be performed, it is important to share physical information on the patient with other departments in preparation for future tests. This will make things easier for those performing the tests and will also give the patient a sense of security.

② What kind of clothing is worn for X-ray tests?

Many imaging tests in the radiology department require the patient to change out of their clothes and into examination clothing. This is difficult for some patients, so every patient should be asked before the examination if they need assistance in changing.

Two types of clothing are used at our hospital: a pajama-type set with a jacket that is tied at the front, and a one-piece gown that is put on over the head.

In order to ensure ease of changing clothes, preparations should be made in advance to enable patients to select the type of examination clothing.

Many patients with upper limb reduction defects find it difficult to wear the pajama jacket as this must be tied at the front. A one-piece gown should be provided for such patients.

③ Please discuss the body positions during X-ray.

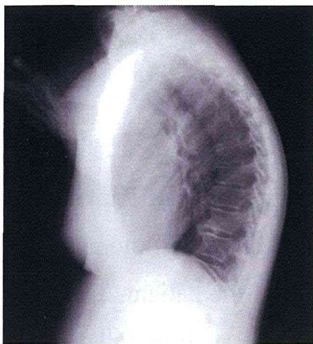
Some patients complain of pain when undergoing tests and scans while lying down. It is, therefore, important that patients undergo imaging in as comfortable a position as possible by, for example, adjusting pillow height, placing cushions or towels beneath the feet, etc.

3. Comments from radiologists

During lateral chest X-rays, it is very difficult for patients with shortened upper limbs to raise their upper limbs on their own. They should be given help by providing support for both their upper limbs or getting them to hold an IV stand, for example. (Fig 1)

All patients with upper limb reduction defects, regardless of the degree of impairment, can find it painful to maintain the same position when in the decubitus or lateral decubitus position, and should be given help and support according to their needs.

The radiologist must treat such patients with great care and thoughtfulness, as too much distress during X-ray can easily damage the patient's trust in the medical staff.



(Fig. 1)

Hearing-impaired patients

① Preparations before X-ray

Patient information should be checked before the tests, in the same way as for patients with upper limb reduction defects.

If the patient is accompanied by a sign-language interpreter, the overall test procedure and specific details of the test should be explained through the interpreter before entering the imaging room. The patients should also be asked if they have any questions.


② Points to remember during tests

Instructions should be conveyed in writing or through gestures and lip reading in the imaging room. Most hearing-impaired patients use lip-reading, so you should remove your mask and speak slowly. The test procedure and specific instructions can be easily explained to the patient using cards etc. (Fig. 2.3). The use of photographs or illustrations is also effective in showing the patient what the test will be like.

Distress can quickly be alleviated if the radiologist gets the patient to give an obvious signal when in pain or discomfort during the test.

初めに胸部のレントゲン撮影を行います。

- ・ この台に胸と顎をつけて下さい。少し台が上下に移動します。
- ・ 続いて腕を台の脇に出して下さい。
- ・ 肩を一度叩いたら、息を大きく吸って止めて下さい。
- ・ 肩を二度叩いたら、息を楽にして下さい。




(Fig 2)

- ・ 右を向いて下さい。
- ・ 両腕を上げて下さい。
- ・ 腕が上がらない場合は補助を致します。

痛みがある場合は首を横に振ってお知らせ下さい。

- ・ 肩を一度叩いたら、息を大きく吸って止めて下さい。
- ・ 肩を二度叩いたら、息を楽にして下さい。



(Fig 3)

Q3-3: What points should be considered when measuring bone mineral density?

- The lumbar spine and proximal femur need to be measured.
- 13% of male patients have osteoporosis based on lumbar spine YAM (PR).

(YAM: Young Adult Mean, PR: Peak Reference)

We compared lumbar spine YAM (PR), femoral neck YAM (PR) and total hip YAM (PR) in 44 thalidomide-impaired patients.

Osteoporosis was found in 13% of men and 4% of women based on lumbar spine YAM (PR), 6% of men and 14% of women by femoral neck YAM (PR) and 0% of men and women according to total hip YAM (PR). In a report on the prevalence of osteoporosis in the lumbar spine and femoral neck in those aged ≥ 40 years old, estimated from the criteria of the Japanese Society for Bone and Mineral Research, the prevalence of osteoporosis of the lumbar vertebrae L2-4 is 3.4% in men and 19.2% in women, and that in the femoral neck is 12.4% in men and 26.5% in women. When comparing our results against these criteria, the prevalence of osteoporosis of the lumbar spine was higher in men, although the prevalence of osteoporosis of the lumbar spine was lower in women.

The prevalence of the femoral neck was lower in both men and women. (Fig. 1, Fig. 2, Fig. 3, Fig. 4, Fig. 5, Fig. 6)

3. Comments from radiologists

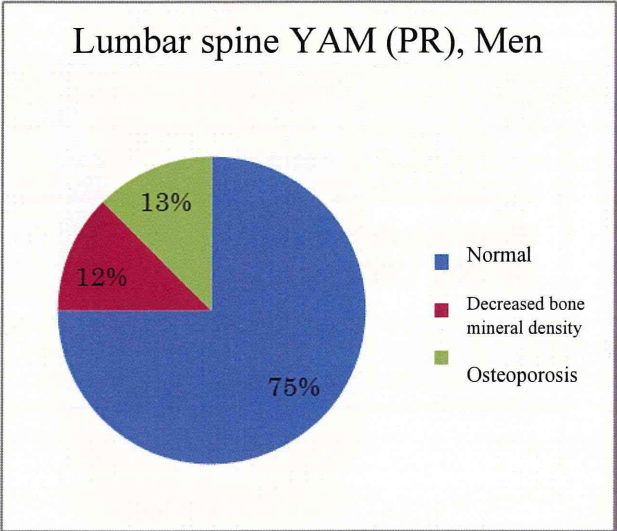


Fig. 1

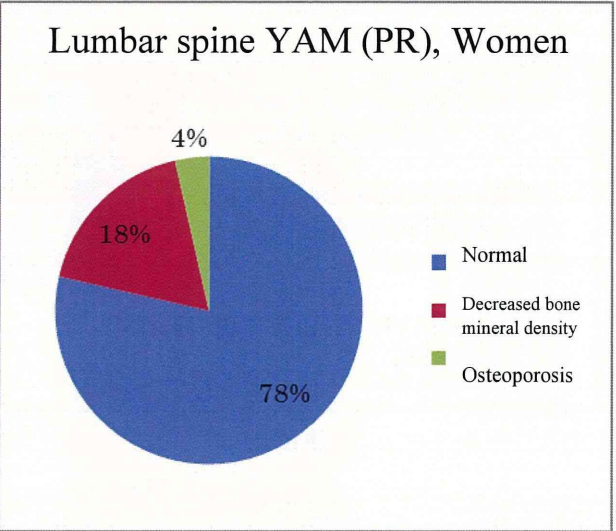


Fig. 2

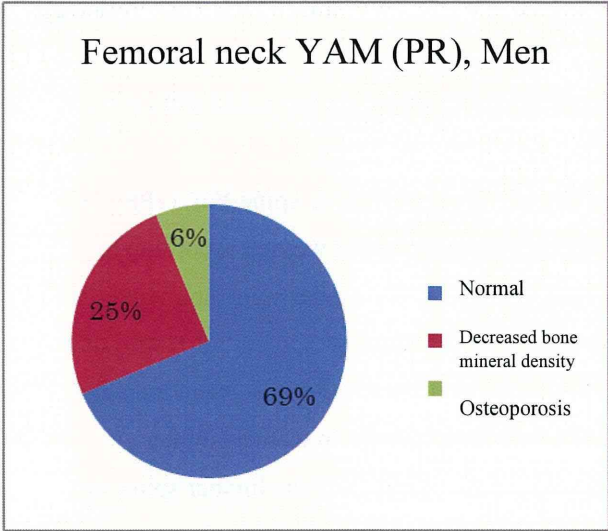


Fig. 3

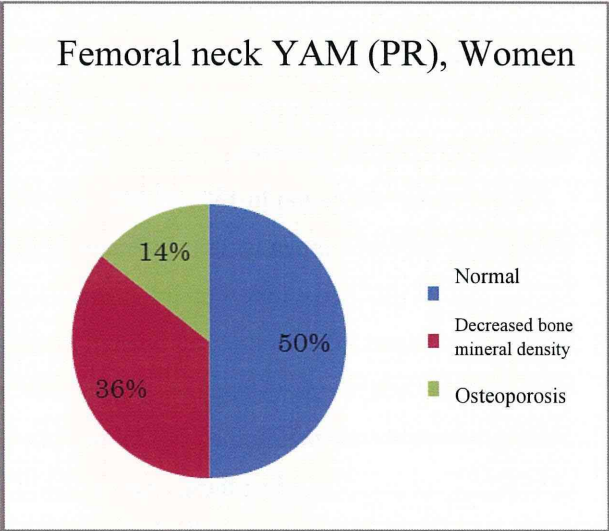


Fig. 4

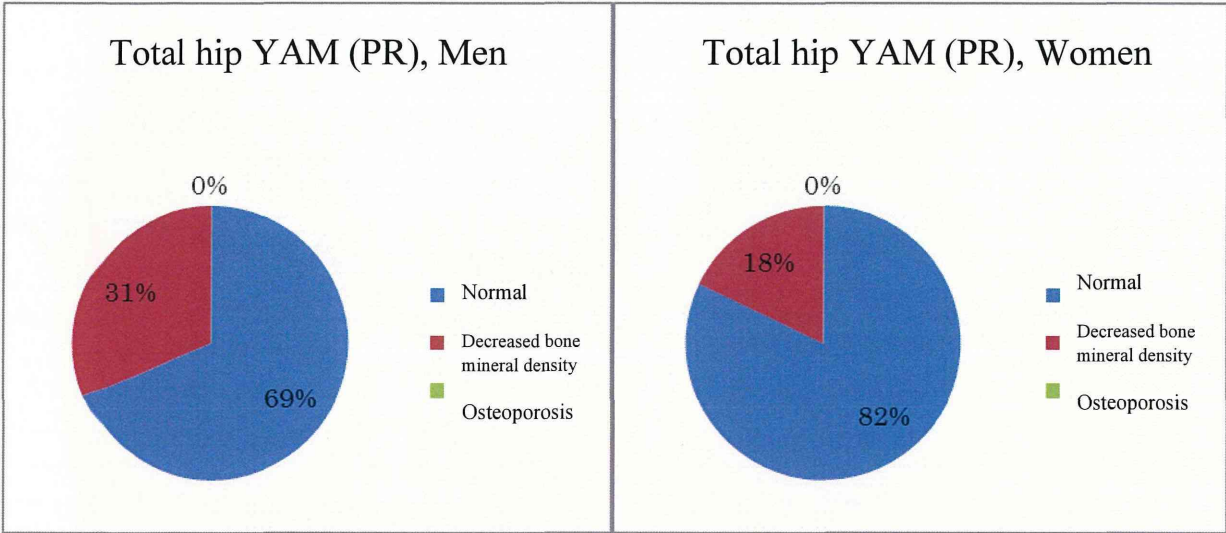


Fig. 5

Fig. 6

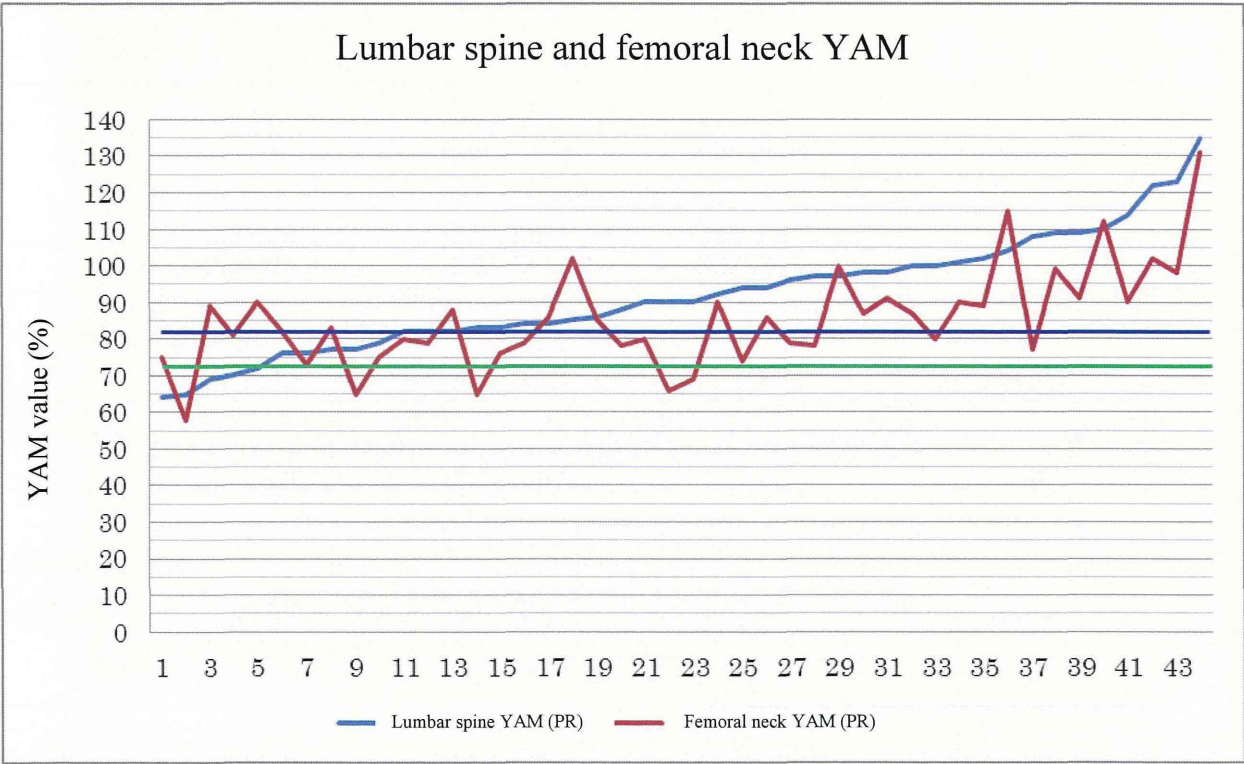


Fig. 7

3. Comments from radiologists

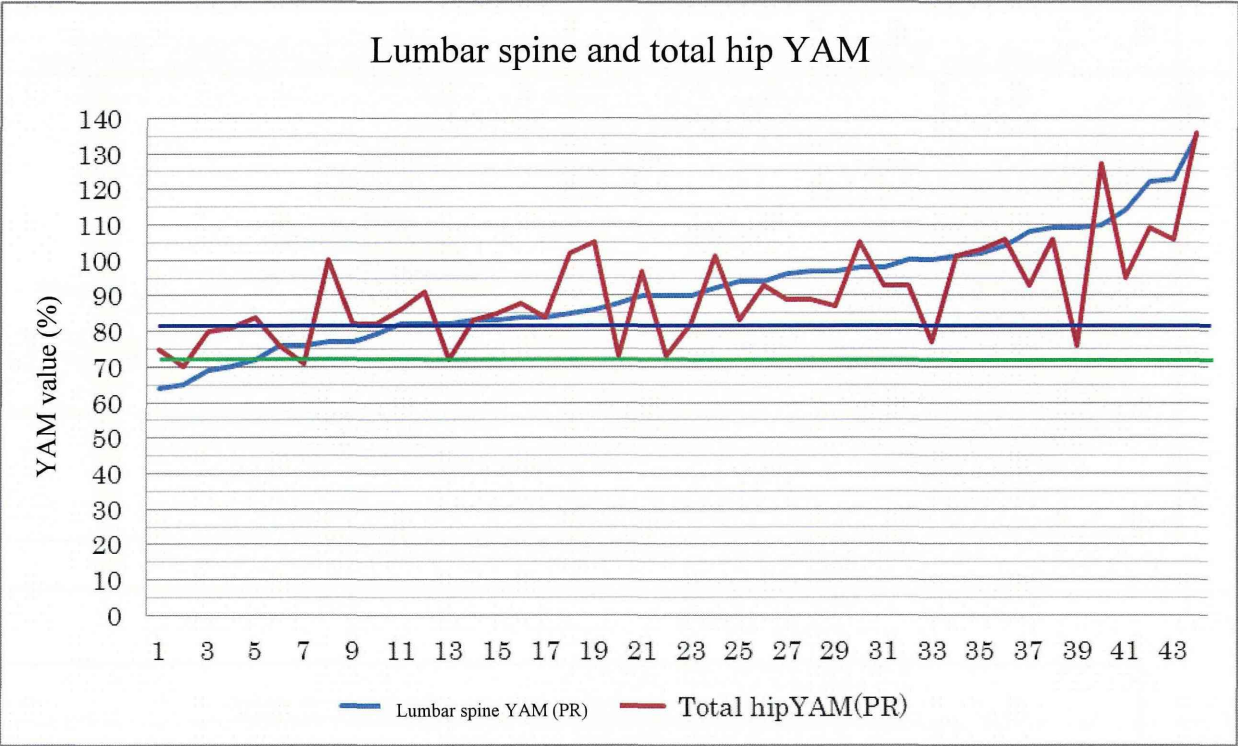


Fig. 8

YAM value	Lumbar spine and femoral neck		Lumbar spine and total hip	
	Men	Women	Men	Women
0-10	7	14	10	17
≥11	9	14	6	11

Table 2

When lumbar spine YAM is high, femoral neck and total hip YAM values also increase. However, quite a few people had YAM values of 11 or above for the lumbar spine and femur. This means there is a risk of missing abnormal values in the femur in cases where only measurement of the lumbar spine is performed. (Figs 7, 8, Table 2)

The relationship between the femoral neck and total hip is similar, with the total hip YAM tending to be higher than the femoral neck YAM. (Fig. 9)

These results suggest that both the lumbar spine and femur should be tested and abnormal values looked for when measuring bone mineral density in thalidomide-impaired patients.

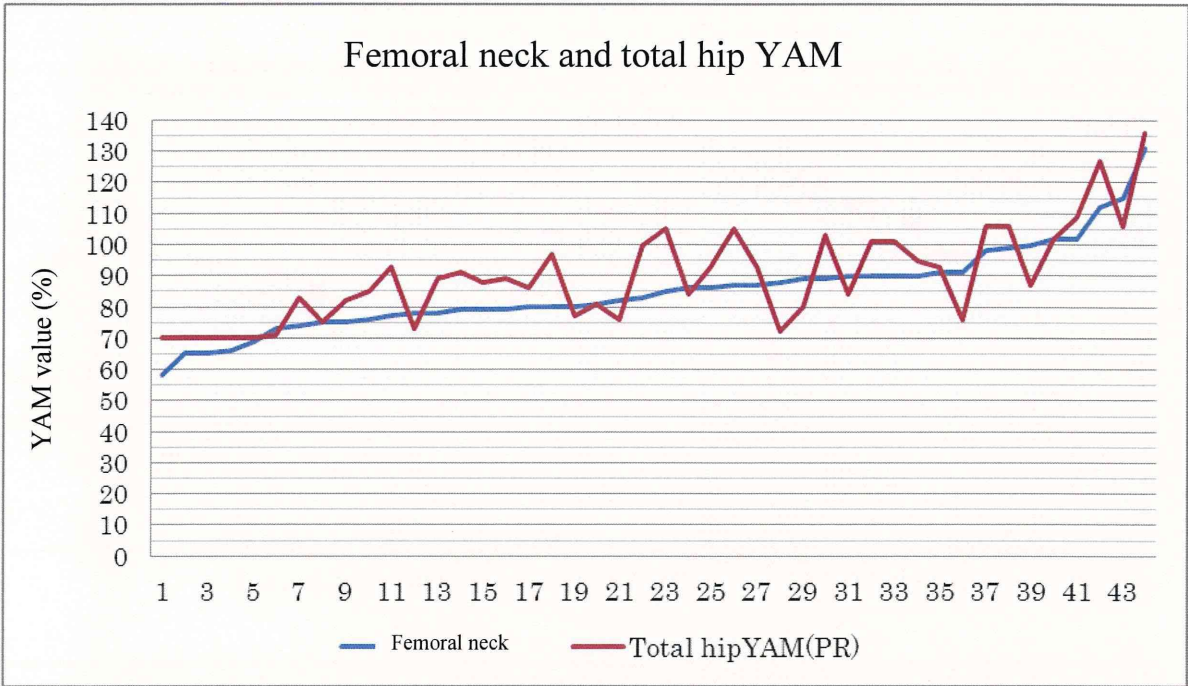


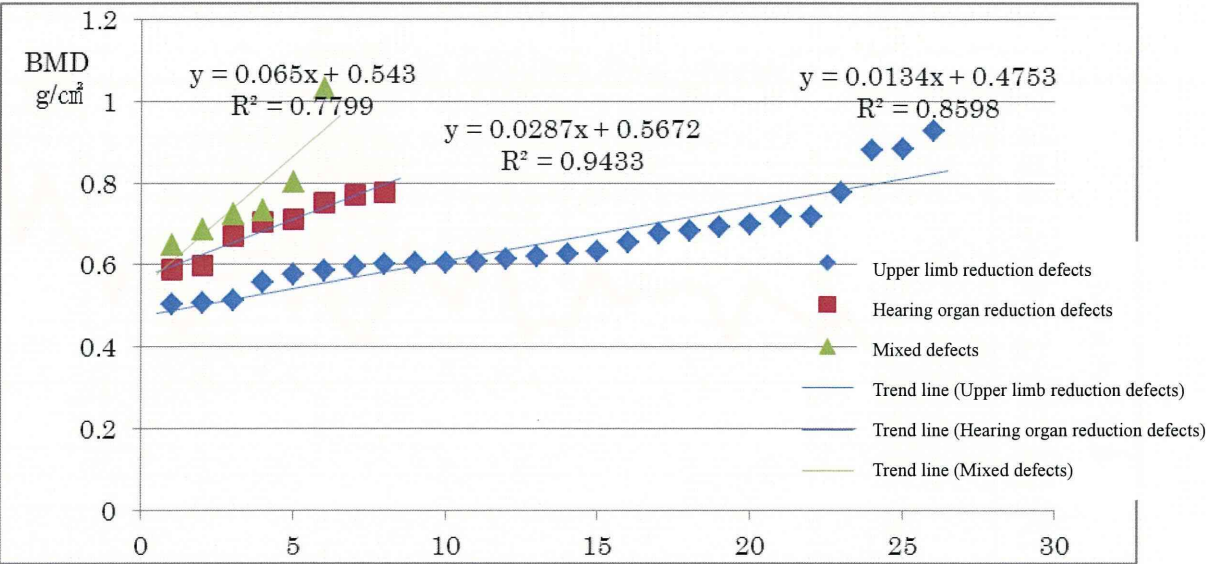
Fig. 9

Q3-4: Are there any particular trends in the bone mineral density of thalidomide-impaired patients?

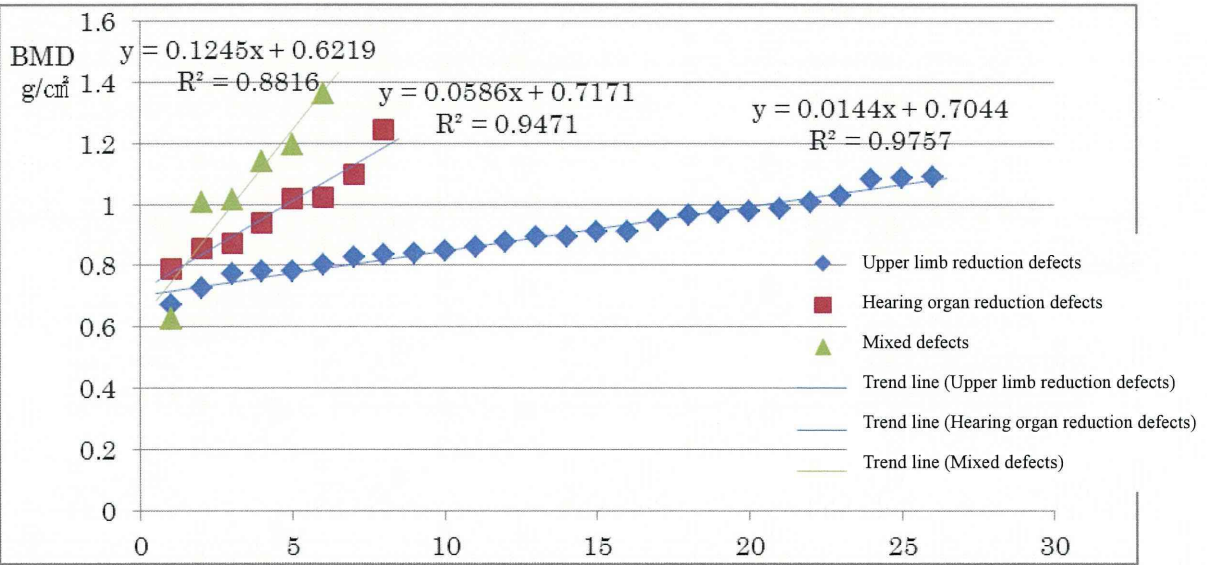
- Bone mineral density at the femoral neck is low (YAM = 76%) in patients with upper limb reduction defects.
- Bone mineral density tends to be low in patients of short stature and low body weight.

In bone density measurements in 40 thalidomide-impaired patients (upper limb reduction defects: 26 patients; hearing organ reduction defects: 8 patients; mixed type: 6 patients), low bone density was seen in about 60% of patients. When comparing the three types, bone mineral density was lowest in those with upper limb reduction defects, followed by those with hearing organ reduction defects and those with mixed defects. (Fig.1)(Fig. 2)

3. Comments from radiologists



(Fig. 1) Comparison of bone mineral density (BMD) values in the femoral neck



(Fig. 2) Comparison of bone mineral density (BMD) values in the lumbar spine

In those with upper limb reduction defects, the mean femoral neck bone mineral density value was 0.66, which is 76% when converted to the YAM value. On the other hand, the mean lumbar spine bone mineral density value was high, at 0.9. When converted to the YAM value this is 88.5%, which is unexpected in view of the changes resulting from thalidomide impairment

In infancy, which is a time of vigorous growth and development with increased bone formation and bone metabolism, patients with upper limb reduction defects would probably not have exposed the bones to sufficient loading because of restricted mobility. With insufficient bone loading, there is a paucity of calcium deposition and the marked inhibition of bone mass increases. Also, the outward

appearance of those with upper limb reduction defects would tend to lead to negative social experiences, social withdrawal and fewer opportunities to go outside. This in turn would reduce the length of time exposed to sunlight, making it difficult for the body to synthesize vitamin D that aids in the absorption of calcium, thus inviting low bone mineral density.

In terms of nutritional balance, those with upper limb reduction defects would probably have greater difficulty than normal people in attaining an adequate dietary intake, and without a balanced diet, calcium intake would decrease and bone mineral density would be unlikely to increase. When the YAM value is below 80%, the question of dietary intake must be tackled with great care and consideration.

No abnormalities of the upper or lower limbs were seen in those with only hearing organ reduction defects, and because this group was less limited in their physical activity than those with upper limb reduction defects, we would expect a tendency for their bone mineral density to be higher.

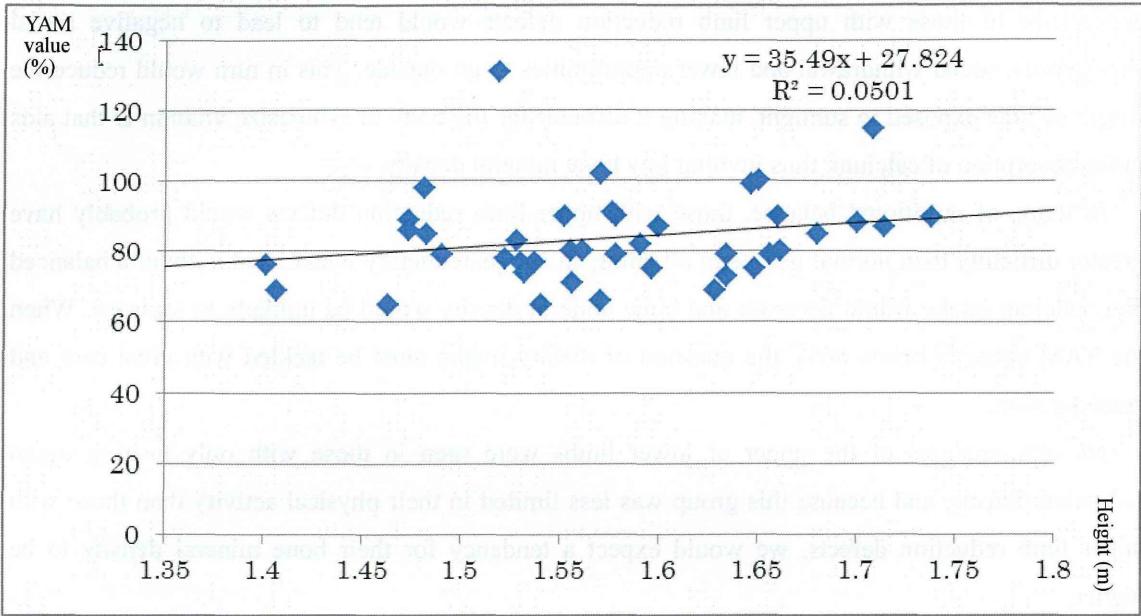
In this analysis, we found that low bone mineral density was much more pronounced in the femoral neck than the lumbar spine. Femoral neck fractures can leave patients bedbound and has a 5-year survival rate of 50%, indicating that those at risk must be carefully monitored.

Bone mineral density was lower in those of shorter stature and lower body weight. (Fig. 3, Fig. 4, Fig. 5, Fig. 6)

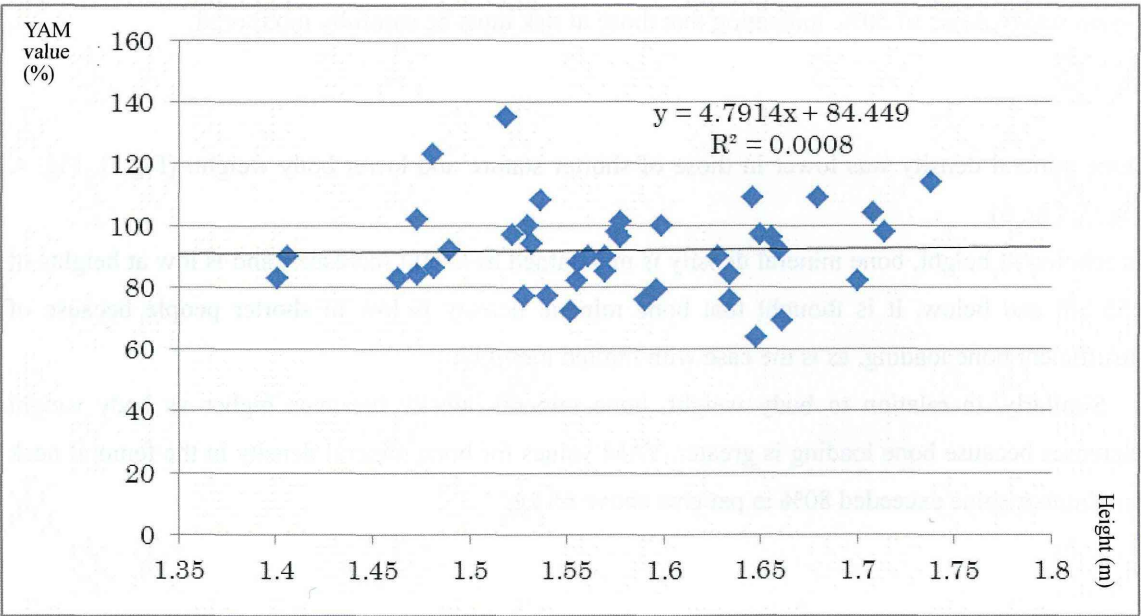
In relation to height, bone mineral density is maintained as height increases, and is low at heights of 155 cm and below. It is thought that bone mineral density is low in shorter people because of insufficient bone loading, as is the case with limited mobility.

Similarly, in relation to body weight, bone mineral density becomes higher as body weight increases because bone loading is greater. YAM values for bone mineral density in the femoral neck and lumbar spine exceeded 80% in patients above 65 kg.

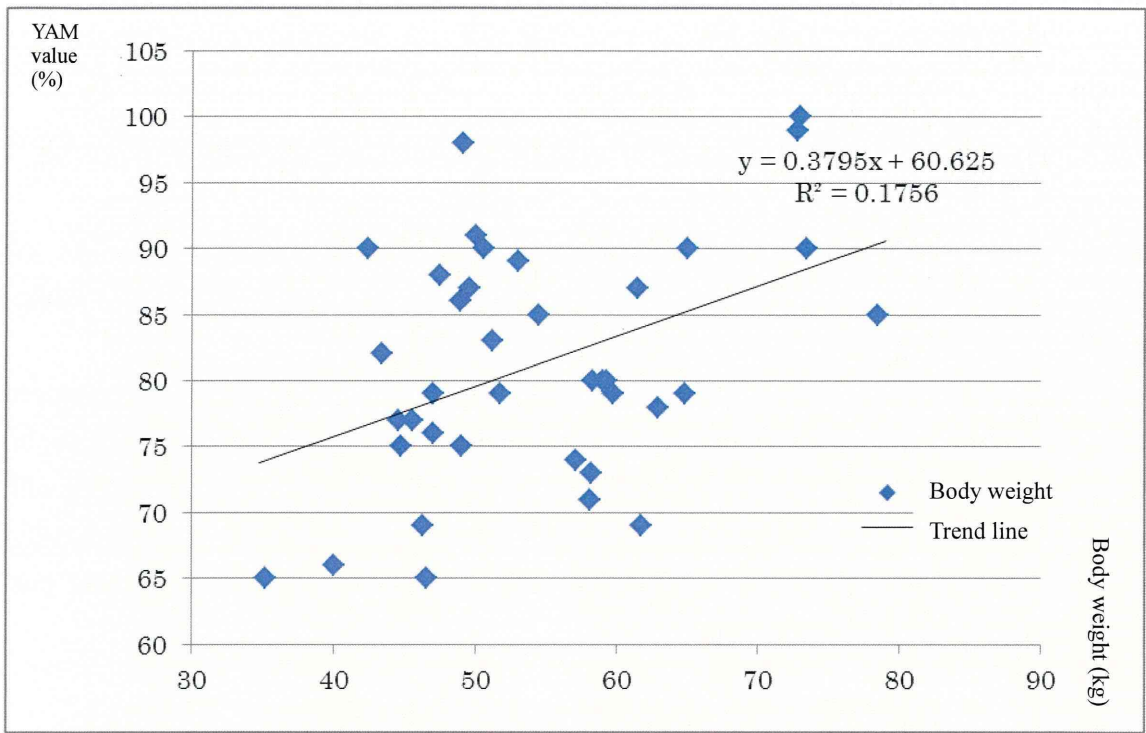
3. Comments from radiologists



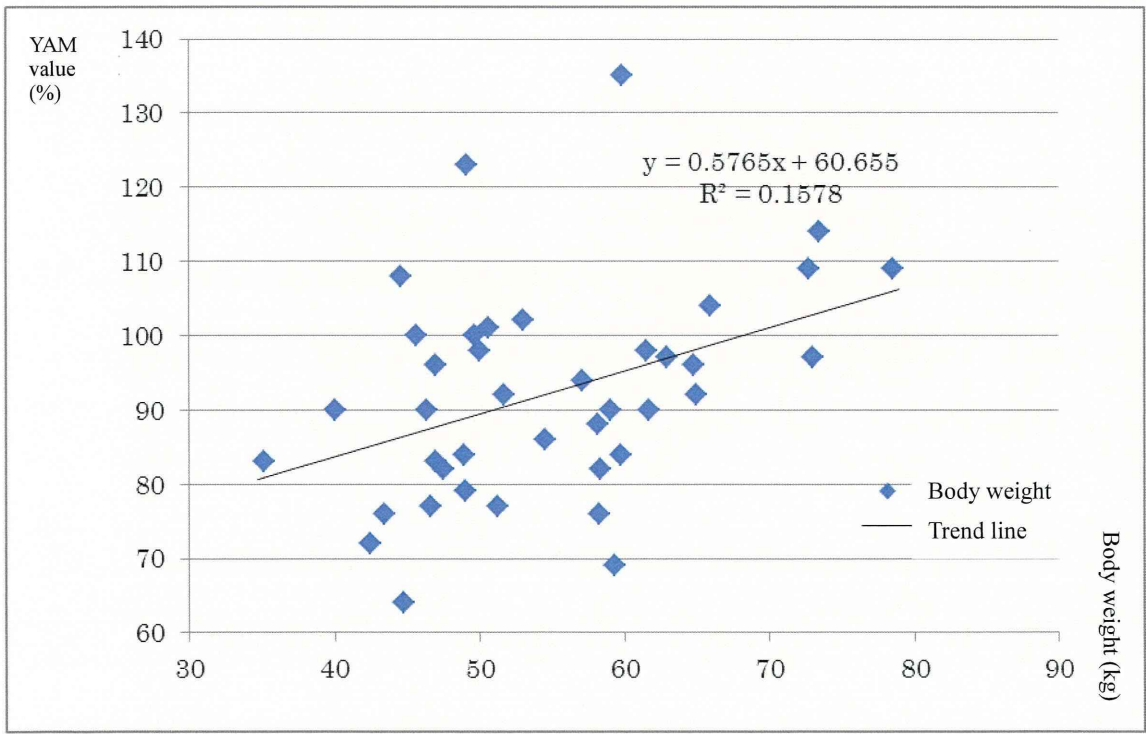
(Fig. 3) Comparison of height and YAM values in the femoral neck



(Fig. 4) Comparison of height and YAM values in the lumbar spine



(Fig. 5) Comparison of body weight and YAM values in the femoral neck



(Fig. 6) Comparison of body weight and YAM values in the lumbar spine

3. Comments from radiologists

Bone mineral density was clearly low in the femoral neck in those with upper limb reduction defects. For such patients, there is a high risk of falling, with the potential fractures having greatly detrimental effects on quality of life (QOL). We hope that by sharing these results with healthcare teams, we can help to maintain the QOL of these patients. This information also needs to be closely shared with regional healthcare centers.

As a result of this analysis, it is possible to inform patients of the high risk factors for osteoporosis, and to advise them on how to prevent osteoporosis themselves through calcium intake, physical activity, etc.

Many thalidomide-impaired patients have inevitably suffered from retarded bone development and reduced muscle strength because of the severe limitations in their activities of daily living due to functional and anatomical impairments of the upper limbs from birth. As these patients age, they will also develop secondary disabilities, but we hope that even though their ability to perform daily activities may become progressively impaired, this research will help in preventing fractures that could severely harm their quality of life.

4. Comments from occupational therapists

Main author: Takeshi Kobayashi

Q4-1: I have very stiff shoulders. Would it be alright to get a massage?

Stiffness from the neck to the shoulders is a problem for many thalidomide-impaired people, and may also include numbness in the arms, hands and fingers. Many people with shortened arms or with one arm much shorter than the other have muscle stiffness over the entire area from the neck to shoulder blades, not just in the shoulders. Massage will be effective if it can alleviate the stiffness, but you should first have your shoulders examined by, for example, the orthopedic surgery department and getting it X-rayed. Although this problem is generally called 'shoulder stiffness', it can be caused by issues such as abnormalities of the neck bones; hence, caution is needed before getting the area massaged. Even after a normal first checkup, it is a good idea to have regular tests and checkups. (See Q2-1)

Q4-2: I have pain in my lower back. Would it be alright to get a massage?

Many thalidomide-impaired people also suffer from low back pain (lumbago). Those with shortened arms, in particular, often use the whole body when reaching for things with the hands. This puts a burden on the lower back. Sufferers may also have numbness in the backs of the thighs and in the toes. Massage should be effective in loosening up the muscles, but you should first have the problem investigated by, for example, consulting the orthopedic surgery department and getting an X-ray. Although this problem is generally called 'low back pain', it can also be a result of abnormalities in the bones of the lower back, which requires caution. Even after a normal first checkup, it is a good idea to have regular tests and checkups. (See Q2-2)

Q4-3: I have developed pain in my hip joints and greater difficulty in moving. When I was examined at a hospital, I was told it was just part of the aging process, but I am worried that I may become immobile if nothing is done.

Pain and restriction of movement in the hip and knee joints are certainly a reality for many people as they get older. Women, in particular, may have hip joint impairments or one leg shorter than the other. Treatments, such as exercise therapy, may be recommended depending on the results of physical examination. In some cases, it is not only the joints that are affected, but the muscles may also have stiffened or contracted. This also requires suitable examination, and can often be

4. Comments from occupational therapists

improved or prevented from getting worse by stretching. It is particularly important to prevent these problems in patients with shortened arms, as they often use their legs for performing day-to-day activities. Hence, you should have the problem investigated by, for example, consulting the orthopedic surgery department and getting an X-ray. (See Q2-5)

Q4-4: I am worried because my posture is gradually getting worse. My body is beginning to look stooped.

This is common in people with upper limb impairments, particularly those with shortened arms. Such people are prone to developing a rounded, stooping posture (kyphosis). This posture is typically caused by habitually slouching when using the hands, so that the whole of the shoulder (the shoulder girdle) sticks forwards. This can easily lead to a feeling of poor posture, fatigue in the muscles around the shoulder and neck, etc. Exercises, such as back stretching, pushing out the chest and opening the arms, are useful. These should be done slowly, with big movements, but without overstraining yourself. It is better to do a few sessions of these every day, several times a session, rather than doing many repetitions all at once. For example, you could do three sessions a day, morning, daytime and evening, performing each exercise 3 times in a session, slowly and with big movements. Try the approach that best suits your physical condition and pace. You might also get some ideas by listening to the morning exercises broadcast over the radio in Japan (*rajio taiso*).

If you feel numbness in the arms, legs or feet, or pain in the neck or lower back, please have the problem investigated by, for example, consulting the orthopedic surgery department and getting an X-ray.

4. Comments from occupational therapists

Q4-5: I have recently started noticing many difficulties in my activities of daily living, such as trouble getting my arms through sleeves when getting dressed, trouble opening bottles, etc.

It is difficult to say whether these recent problems with deterioration of joint movement, loss of strength and so forth are directly related to age or to thalidomide-induced impairments. It must also be worrying to find that you are able to do less and less, especially as you have had to make great efforts to find ways of coping with everyday activities since infancy. In the future, you will probably need to continue to maintain joint mobility and muscle strength in a way that suits your own style and pace. But you should be careful not to overdo things, as you will cause yourself pain if you overburden your joints and muscles. In future, it will also be important to use equipment such as self-help aids to make things easier in your daily life while alleviating the burden on your body. If there is an occupational therapist at a local healthcare center, please ask them about self-help aids and assistive devices^{Note}.

Q4-6: I regularly use a computer for my job, but I am getting numbness in my hands and fingers. Recently I have had difficulty using a mouse.

The main cause of computer work-related numbness in the hands and fingers is carpal tunnel syndrome, and this is a widespread problem not restricted to thalidomide-impaired people. Nevertheless, caution is needed as thalidomide-impaired people are inherently more prone to develop carpal tunnel syndrome. Commercially available wrist pads are generally used to ensure that the wrist joints are bent downwards rather than upwards. The pad height defines the angle of the wrist joint, but everyone is different, so you should experiment with different heights and materials. The mouse can also be adapted to suit the individual, as the hands and fingers of thalidomide-impaired people typically differ in terms of length and structure. If you are able to consult with an occupational therapist with knowledge of self-help aids, they should be able to find a solution tailored to your specific needs^{Note}. (See Q2-3, Q2-4)

Q4-7: I get dry eyes and have difficulty seeing around me when I move my eyes.

This is a common problem in people with impaired hearing, particularly those with paralysis of the facial muscles. These people can have various other symptoms apart from dry eyes, such as watery eyes. Firstly, you should have this investigated by the ophthalmology department. The difficulty in seeing around you when you move your eyes could be because the small muscles that

4. Comments from occupational therapists

make your eyeballs move are not working enough. There are various approaches to this problem depending on the symptoms, so please arrange to be seen by a hospital or clinic that has an orthoptist. (see Q1-4).

Q4-8: I am anxious because my parents are beginning to need nursing care and I am not sure how the long-term care insurance system works.

Your parents must be around 75 years old or more, so it is understandable that they will gradually need help. In Japan, long-term care insurance is generally available to people aged 65 and over, but applicants must obtain certification by applying to the municipality where they reside. Upon application, the degree of care required is determined, which dictates the kind of service you receive. After obtaining certification, you will need to choose a care manager. The care manager will create a care plan in consultation with the person requiring care and their family. The care plan should be selected in accordance with the wishes of the person requiring care, as there are various aspects to the plan, such as day services or home visit services, provision or loan of assistive devices and aids, etc. As a general rule, copayment by the recipient for use of these services is set at 10%. Please enquire at the relevant department of your local municipality (e.g. the Senior Citizens Welfare Division).

Q4-9: Is long-term care insurance also available to thalidomide-impaired people? What other help is available?

In principle, long-term care insurance is intended for people aged 65 and over. From the age of 40, you can only receive this insurance if you have a 'specified disease' (e.g. cerebrovascular disease, Parkinson's disease, rheumatoid arthritis, etc.). Unfortunately, thalidomide impairment is not currently one of the specified diseases, so thalidomide-impaired people cannot use long-term care insurance at this age. Under the *Services and Supports for Persons with Disabilities Act*, people with disabilities could receive certification for a particular disability level classification from the municipality where they live, following a similar procedure as the long-term care insurance procedure. However, this law was replaced by the *Act for Comprehensive Support of Daily and Social Activities for Persons with Disabilities* on April 1st, 2013, so please consult with the secretary of the Ishizue Foundation for more information.