

	障害区分情報など	上肢障害	聴覚障害	塊椎	無胆嚢症	大腿骨全体	頸部	腰椎
57	上肢	○	×			ND	ND	ND
58	聴覚・顔面麻痺	×	○			ND	ND	ND
59	上肢	○	×		○	ND	ND	ND
60	上肢	○	×		○	ND	ND	ND
61	上肢	○	×			ND	ND	ND
62	上肢	○	×			ND	ND	ND
63	上肢・聴覚・顔面麻痺	○	◎	変形性頸椎症	×	ND	ND	ND
64	上肢・聴覚・外転神経麻痺	◎	○	変形性頸椎症		ND	ND	ND
65	聴覚・顔面麻痺	×	○			ND	ND	ND
66	上肢・耳介低形成	◎	○			ND	ND	ND
67	上肢	○	×			ND	ND	ND
68	上肢	○	×			ND	ND	ND
69	上肢・心室中隔欠損	○	×			ND	ND	ND
70	聴覚・顔面麻痺	×	○			ND	ND	ND
71	上肢	○	×			ND	ND	ND
72	上肢・耳介異形成・心雑音	○	×			ND	ND	ND
73	上肢・聴覚・顔面麻痺	○	×			ND	ND	ND
74	聴覚	×	○			ND	ND	ND
75	上肢・聴覚	○	×			ND	ND	ND
76	上肢	○	×			ND	ND	ND
平均値						90	85	91
最高値						136	131	134
最低値						70	58	57

○:後天的な聴覚障害が疑われる

資料5: CT側頭骨所見

	障害区分情報など	上肢障害	聴覚障害	側頭骨	側頭骨所見
1	上肢・聴覚	○	◎	○	両側とも前庭から蝸牛にかけて嚢胞状。後半規管は形成、その他の半規管は形成不全。
2	上肢・聴覚・顔面麻痺	○	◎	○	両側内耳・中耳奇形。特に右は重篤な蝸牛y神経の低形成。両側顔面神経低形成。両側性の先天性外転神経麻痺によるデュアン症候群。
3	上肢・聴覚	○	◎	○	左内耳は蝸牛と前庭が嚢胞状。右内耳は蝸牛と前庭が連続する一つの楕円形の一つの腔。三半規管は両側とも後半規管は確認できるが、前半規管は認められず。
4	上肢・聴覚・外転神経麻痺	◎	○	○	両耳中耳内耳奇形。外耳道狭窄。内耳道低形成。両側とも蝸牛が無く蝸牛神経も無形成。
5	上肢・耳介低形成	◎	○	○	右耳小骨単脚
6	母指球筋低形成・聴覚	◎	○(右>左)	ND	
7	上肢・聴覚	◎	○	×	
8	上肢・聴力	○	○	ND	
9	上肢・聴覚・言語	○	◎	○	右側きぬた骨形成不良、あぶみ骨欠損。左側きぬた骨形成不全、あぶみ骨矮小。両側三半規管の形成不全。
10	聴覚・視力・顔面麻痺	×	○	○	耳小骨形成不全、左前庭が嚢胞化、概則半規管が低形成。右は異常なし。
11	聴覚・顔面麻痺	×	○	○	両側とも内耳道が認められず、右側は蝸牛、三半規管は痕跡的。左側では蝸牛、三半規管に相当する部位が一つの嚢胞状。左側のあぶみ骨はほとんど確認できず、右側のあぶみ骨は矮小。
12	聴覚	×	○	○	両側耳小骨低形成。両側外半規管が小さい。左外耳道は閉塞。
13	聴覚・外転神経麻痺	×	○	○	両側耳介欠損、両側外耳道閉鎖、右側は膜様閉鎖、左側は骨性閉鎖。両側とも耳小骨は形成が悪く、あぶみ骨は両側とも同定できず、つち骨・きぬた骨も形成不良。内耳蝸牛は形成不全、前庭は嚢胞状。後半規管はループを形成せず円弧状構造、前半規管左側は蝸牛・前庭・三半規管を指摘できず。右内耳道は細く、左内耳道は欠損。
14	顔面麻痺・聴覚	×	○	○	両側外耳道は内側からした外側へ傾斜。内耳の形状も変形、耳小骨の形成に明らかな以上は指定できない。内耳や外側半規管がやや小さい印象があるが内耳の構造に明らかな異常は認めない。
15	顔面麻痺・耳介低形成	×	○	○	左外側半規管低形成、管腔を形成せず前庭と一塊となり嚢胞状。右外側半規管はやや小、管腔形成は見られる。右耳介低形成。右外耳道に膜状の構造物を認めるが完全には閉塞していない。右鼓膜肥大、鼓室や乳突洞壁に軟部組織陰影が見られ、乳突蜂巣には軟部組織陰影が充満。耳小骨ではあぶみ骨は同定できず、変形縮小したつち骨ときぬた骨が鼓室全壁に癒着。慢性中耳炎と思われる。
16	聴力	×	○	○	右外耳道低形成、左外耳道閉塞、両側耳小骨奇形
17	聴覚・顔面麻痺	×	○	○	左外耳道閉塞、耳小骨欠損、左内耳奇形。
18	聴覚・顔面麻痺	×	○	○	左:内耳道低形成。内耳common cavity。耳小骨きぬた骨あぶみ骨一部低形成。右:内耳道低形成。内耳低形成Michel deformity。耳小骨あぶみ骨つち骨奇形。外耳道閉鎖症、右のほう为重篤。
19	聴覚	×	○	ND	
20	顔面麻痺・耳介低形成	×	○	ND	
21	顔面麻痺・聴覚	×	○	ND	
22	顔面麻痺・聴覚	×	○	ND	
23	聴覚・顔面麻痺	×	○	○	両側とも内耳道、蝸牛、三半規管に相当する構造が見られず。両側外耳道屈曲した走行。耳小骨は認められるが、つち骨あぶみ骨は変形し骨壁に癒合。
24	上肢・聴覚・顔面麻痺	○	×	○	右耳小骨は外側へ偏位。右内耳道は認められず、前庭、蝸牛、三半規管は嚢胞状の単一腔。左聴覚器官に異常なし。
25	上肢・左股関節脱臼	◎	○	○	両側慢性中耳炎、外半規管やや低形成。
26	上肢	○	×	×	右側の内耳道やや狭小。
27	上肢	○	×	○	両側外側半規管が低形成で前庭と癒合。
28	上肢・耳介異形成・心雑音	○	×	○	両側外側半規管の低形成。
29	上肢	○	×	○	右慢性中耳炎、左乳突蜂巣内少量液体貯留
30	上肢・心奇形	○	×	○	右内耳道の不整な拡張。
31	上肢	○	×	○	左ツチ骨頭と鼓室壁との骨性の癒着
32	上肢	○	×	○	右乳突蜂巣は発達不良。慢性中耳炎。

	障害区分情報など	上肢障害	聴覚障害	側頭骨	側頭骨所見
33	上肢	○	×	○	両側あぶみ骨の形成不全。 乳突蜂巣の発育が著明
34	上肢	○	×	×	
35	外転神経麻痺・わにの涙症	×	×	ND	
36	上肢・聴覚	○	×	×	
37	上肢・聴覚	○	×	×	
38	上肢	○	×	×	
39	上肢・聴覚	○	×	×	
40	上肢・聴覚	◎	○(左右)		
41	上肢	○	×	×	
42	上肢・眼球運動障害	○	×	×	
43	上肢	○	×	×	
44	上肢	○	×	×	
45	上肢・歩行障害	○	×	×	
46	上肢	○	×	×	
47	上肢・わにの涙症	◎	○	×	
48	上肢・耳介異形成	○	×	×	
49	上肢	○	×	×	
50	上肢・心室中隔欠損	○	×	×	
51	上肢	○	×	×	
52	上肢	○	×	×	
53	上肢	○	×	×	
54	上肢	○	×	×	
55	上肢	○	×	×	
56	上肢	○	×	×	
57	上肢	○	×	×	
58	上肢	○	×	×	
59	上肢	○	×	×	
60	上肢	○	×	×	
61	上肢	○	×	×	
62	上肢	○	×	×	
63	上肢	○	×	ND	
64	上肢	○	×	ND	
65	上肢	○	×	ND	
66	上肢・わにの涙症	○	×	ND	
67	上肢	○	×	ND	
68	上肢	◎	左○	ND	
69	上肢	○	×	ND	
70	上肢	○	×	ND	
71	上肢	○	×	ND	
72	上肢	◎	左○	ND	
73	上肢	○	×	ND	
74	上肢	○	×	×	
75	上肢	◎	○	×	
76	上肢	○	×	×	

上肢の障害で採血・血圧測定が困難なサリドマイド胎芽病者の健診手順の考え方

1) 腹部超音波検査

先天性
無胆嚢症(+) 10/76(13%)

塊椎疑い
4/10(40%)

頸椎XP・MRI

脂肪肝(+) 40/76(52.6%)

脂質異常症疑い

血液生化学検査

脂質異常症(+)

栄養指導

2) 下肢(後脛骨動脈)血圧測定 (収縮期血圧+8)×0.88mmHg

BPs: 145mmHg 以上

高血圧疑い

血液生化学検査
・尿検査
・眼底評価

家庭血圧測定

3) 心電図

Sokolow-Lyon index
SV1+RV5 ≥ 3.5mV
または
R5 or R6 ≥ 2.6mV

左室肥大疑い

心臓超音波検査

左室肥大(+)

資料 6 図.1

Health check procedure for thalidomide impaired people with upper limb impairment who are difficult to take blood and measure blood pressure

1) Abdominal ultrasound

Congenital
agenesis of
the gallbladder (+)
10/76 (13%)

Fatty liver (+)
40/76 (52.6%)

Block vertebra
is suspected
4/10 (40%)

Dyslipidemia is
suspected

cervical vertebrae
XP-MRI

Blood chemistry test

Dyslipidemia (+)

Nutritional guidance

**2) Measurement of blood pressure
in lower limb (posterior tibial artery)**

(systolic blood pressure + 8) × 0.88mmHg

BPs: Over 145mmHg

High blood pressure
is suspected

- Blood chemistry test
- Uren test
- Funduscopy

Blood pressure measurement at home

3) Electrocardiogram

Sokolow-Lyon index
SV1 + RV5 ≥ 3.5mV
Or
R5 or R6 ≥ 2.6mV

Left ventricular
hypertrophy is suspected

Echocardiography

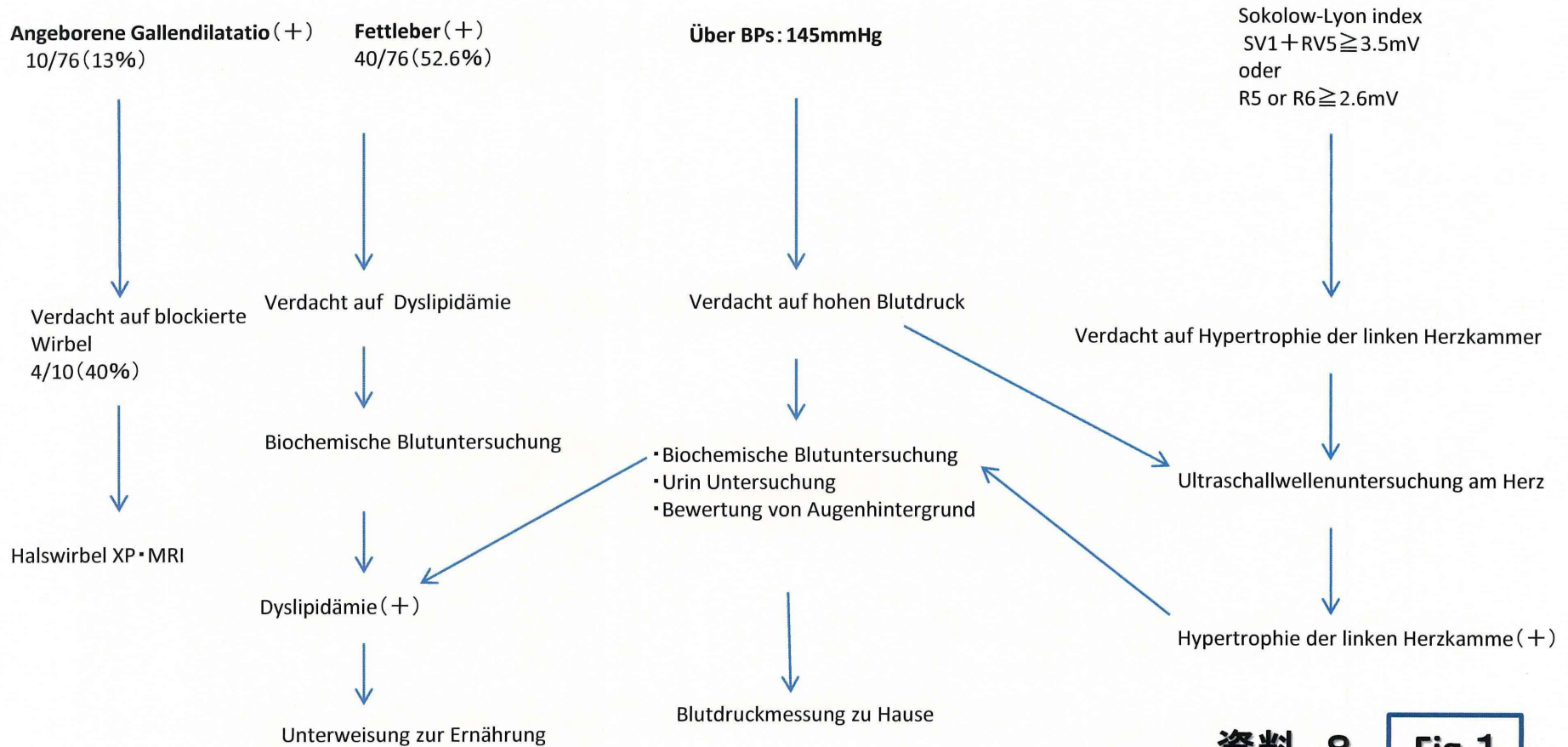
Left ventricular
hypertrophy (+)

Denkweise über die Reihenfolge der Gesundheitsuntersuchung bei Personen die im Embryostadium an Contergan erkrankt sind und deren Blutabnahme-Blutdruckmessung wegen der Behinderung am Oberarm schwierig ist.

1) Ultraschallwellenuntersuchung am Bauchbereich

2) Blutdruckmessung am Bein (Hintere Schienbeinarterie)
($\text{Systolischer Blutdruck} + 8$) $\times 0.88$ mmHg

3) EKG



資料 8

Fig. 1

(資料 9)

BLOOD PRESSURE

We know that smoking is a health risk and indeed it is easy to see when someone is smoking and to identify them as having a health risk.

Unfortunately high blood pressure is a very significant health risk and is often hidden. If one's blood pressure becomes very high then sometimes this may be associated with various symptoms including headaches. Unfortunately, however, damaging levels of high blood pressure are often present without any symptoms.

Uncontrolled High Blood Pressure is one of the commonest causes of stroke in the UK today.

Despite a drive by the National Health Service to encourage general practitioners to monitor people's blood pressures there is still a significant portion of the normal population that have not had their blood pressure adequately reviewed.

Thalidomiders are not immune to the dangers of high blood pressure and should all make sure that their blood pressure is screened regularly.

In those with normal arms such screening should not pose a problem.

In those with abnormal or absent arms screening may be more difficult and those with abnormal arms and legs pose a potential significant problem.

Suggestions:

(please note that this will be updated as information comes to light, we are soon to meet with an interested Cardiologist in London who may well be able to help further)

If you have a relatively normal upper arm your GP or practice nurse should be able to find a suitably sized BP cuff and take your BP.

In those with absent arms the leg can be used, but will need specially sized blood pressure cuffs.

If your GP practice is unable to take your Blood Pressure reliably then they should refer you to someone who can give further advice, a local cardiologist for example. This advice has worked very well in one recent case.

The advisors to the Thalidomide Trust do not consider inability to measure Blood Pressure in a simple way as a good enough reason not to do it! We would encourage all Thalidomiders to insist that this very important preventative medicine practice be made available to them. If you have problems having your BP checked HealthLink would like to hear from you.

Some useful weblinks:

<http://www.bbc.co.uk/health/conditions/hypertension1.shtml>

Here is a good site, meant for health care professionals but this will give anyone who wishes to do further reading a good place to start: <http://www.abdn.ac.uk/medical/bhs/index.htm>

(資料 10)

Q&A on Thalidomide-Impaired People

March 2014

Q&A on Thalidomide-Impaired People

13 February, 2014:

Ver.5-3

This Q&A was put together for doctors, nurses and other healthcare professionals, who need to examine and treat thalidomide-impaired people but are not fully familiar with thalidomide impairment, so please introduce it to doctors and other staff as necessary. This booklet will also be immediately useful for doctors who only have time to read the relevant sections.

We hope that this booklet will help in maintaining health, preventing disease and providing routine medical care for thalidomide-impaired people around the world, over half a century after the deleterious effects of thalidomide first surfaced.

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Recommendations and Suggestions

Recommendations

- 1、 It is strongly recommended that health care workers utilize this Q&A.

- 2、 It is recommended to use automated sphygmomanometer in cuff-oscillometric methods on posterior tibial artery for measuring blood pressure for people with upper limb disabilities.
 - Measurement should be done in recumbent position.
 - When the normal (size M) cuff is used to measure in the method stated above, systolic pressure should be $(\text{posterior tibial artery systolic pressure} + 8) \times 0.88$ mmHg
 - It is recommend to measure blood pressure at home.
 - When arm blood pressure is measured, it is strongly recommended to use cuff that is suited for the upper arm circumference.

- 3、 If a person with upper limb disabilities shows Sokolow-Lyon index $SV1 + RV5 \geq 3.5\text{mV}$ or $R5$ or $R6 \geq 2.6\text{mV}$ in the electrocardiogram, left ventricular hypertrophy is suspected so it is strongly recommended to do an echocardiography.
 - There is a possibility that potential patients with high blood pressure is found.

- 4、 If it is difficult to take blood because of the disability of upper limb, evaluate whether they have fatty liver with abdominal ultrasound.
 - If fatty liver is found, there is a high possibility that they have lipid metabolism abnormality so blood chemistry study is strongly recommended.

- 5、 If they feel pain in forearms and upper arms because of carpal tunnel syndrome, it is strongly recommended to evaluate their cervical vertebrae.
 - There is a possibility that proximal symptom is a sign for cervical spondylosis.

- 6、 It is recommended that upper gastrointestinal endoscopy is done via nasal endoscope by a trained doctor.
 - There is less pain for the patient and sedative is not necessary.

- 7、 It is strongly recommended to not wear a mask when examining a patient with hearing impairment.

- Patients with hearing impairment naturally acquire skills (lip reading) to visually supplement the lack of hearing.
- A doctor should not talk to patients with hearing impairment from the angle where they cannot see the doctor's mouth, such as facing the electronic chart.

8、 It is recommended to use explanation material indicated in this Q&A when examining patient with hearing impairment.

- There may be a necessity for communication by writing so prepare a whiteboard or memo pad.

9、 It is recommended to do health check for 2 people with hearing impairment on the same day.

- They can share a sign language interpreter.
- They feel a sense of security because patients with hearing impairment can communicate with each other.

10、 It is recommended to consider whether they have mental disorder such as depression.

- The results of the survey of actual life situation showed that disease rate is higher (10.4%) than the people in the same generation (2.0%).

Proposals for the way comprehensive assistance to the Thalidomide-impaired people should be

1. To propose to construct the system for providing information and consultation in order to promote the positive use of the system to assist the life of Thalidomide-impaired people.
2. To propose to continuously assist the Thalidomide-impaired people to receive a regular health check because they are more likely to suffer from the lifestyle diseases than general public.
3. To propose to foster doctors and promote medical institutions with whom/which the Thalidomide-impaired people and their doctors in charge can consult about

Q&A on Thalidomide-Impaired People

the treatment principles related to “the pain” and sequelae.

4. To propose to promote international association so that the Thalidomide-impaired people and medical staffs can share the knowledge that has been gained as a result of studies done in Britain, Germany and Japan.

5. To propose to ensure that the medical students study the history of drug disasters and prevention as well as the Relief System for Sufferers from Adverse Drug Reactions.

Continuance of the studies

This study is still continued even after April 2014. The new representative is Fumihiko Hinoshita, Nephrology, National Center of Global Health and Medicine

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Q&A on Thalidomide-Impaired People

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

Q4-3: I have developed pain in my hip joints and greater difficulty in moving.

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

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.

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.

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

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.

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

Q4-10: What is the disability pension? Is this the same as the Ishizue pension, and is it also available to thalidomide-impaired people?

5. Blood collection89

Atsuto Yoshizawa

Q5-1: How do you collect blood from people whose upper limb impairments make this a difficult procedure?

Q5-2: What sort of kit is used for blood collection?

6. Measuring and evaluating blood pressure93

Yuka Shiga, Yasuhiro Maehara, Atsuto Yoshizawa, Hiroyuki Nagase,

Yutaka Seki, Eriko Kanehisa, Takuro Shinbo

Q6-1: How is blood pressure measured in people with upper limb impairments?

Q6-2: How accurate is BP measurement obtained at the posterior tibial artery using an electronic BP monitor?

Q6-3: Assuming there are differences between lower limb and upper limb BP using indirect measurement methods, is there a formula for estimating upper limb BP from BP measured in the posterior tibial artery?

Q6-4: Can BP be measured in the upper limb in people with upper limbs that are underdeveloped but not completely missing?

Q6-5: How should BP be evaluated in people suspected of having peripheral artery disease (PAD)?

Q6-6: Are there any home BP measurement methods that can be used without family

assistance?

7. Comments from nurses99

16F Ward Nurses, National Center for Global Health and Medicine

- Q7-1: How is blood pressure measured?
- Q7-2: How are blood samples obtained?
- Q7-3: Are there any particular techniques for urine sample collection?
- Q7-4: Are there any particular techniques for abdominal ultrasound scans?
- Q7-5: Are there any particular techniques for ECG tests?
- Q7-6: Are there any important points for hearing tests and examinations by the otolaryngology department?
- Q7-7: Are there any particular techniques for upper gastrointestinal endoscopy?
- Q7-8: Are there any other important points relating to tests?
- Q7-9: Are there any important points common to all tests?
- Q7-10: Are there any particular techniques for medical examinations and nutritional guidance?

8. Upper GI endoscopy (via the mouth)103

Toshiyuki Sakurai

- Q8-1: Is the test procedure the same as for other patients?
- Q8-2: How do you monitor blood pressure in patients with missing or underdeveloped upper limbs?
- Q8-3: Are sedatives necessary?
- Q8-4: Are there any important points when administering sedatives?
- Q8-5: What sort of endoscope is used?
- Q8-6: Do patients have difficulty adopting a suitable position for endoscopy?
- Q8-7: Are there any important points when inserting the endoscope?
- Q8-8: Are there any important points regarding endoscopic observation?
- Q8-9: Are there any techniques for getting the patient to relax?
- Q8-10: What strategies are used for those with hearing loss?
- Q8-11: Have there been any abnormal anatomical findings?
- Q8-12: Are there any other important points?
- Q8-13: Are there any important points for nurses attending the test?

9. Upper GI endoscopy (via the nose)107

Takama Maekawa

- Q9-1 : Is the choice between transnasal and transoral routes made in the usual way?

Q&A on Thalidomide-Impaired People

Q9-2: Are any patients contraindicated for transnasal endoscopy?

Q9-3: Is the transnasal endoscopy procedure the same as for normal patients?

Q9-4: Does transnasal endoscopy take the same amount of time to perform as transoral endoscopy?

Q9-5: Are there any precautions to be observed when performing transnasal as opposed to transoral endoscopy?

Q9-6: What brand of transnasal endoscopes do you use?

Q9-7: Are sedatives necessary for transnasal endoscopy?

Q9-8: Is pretreatment for transnasal endoscopy in thalidomide-impaired patients the same as for other patients?

Q9-9: How do you choose between left and right nasal cavities?

Q9-10: Are there any problems with body position during transnasal endoscopy?

Q9-11: Were there any anatomical abnormalities or characteristic abnormal findings?

Q9-12: Did any patients have nosebleeds?

Q9-13: Do these patients need any particular kind of assistance?

10. Anesthesia111

Yuka Shiga, Yasuhiro Maehara

Q10-1: Are there any particular points to be aware of in preoperative rounds?

Q10-2: Are there any contraindications for particular anesthesia methods?

Q10-3: Is premedication necessary?

Q10-4: Are any particular preparations necessary?

Q10-5: How do you monitor blood pressure in patients with missing or underdeveloped upper limbs?

Q10-6: What strategies are used for those with hearing loss?

Q10-7: Is the amount of anesthetic agent the same as for other patients?

Q10-8: Are there any points to consider during intubation?

Q10-9: Are there any important points to consider after surgery?

11. Psychiatry113

Kobun Imai

Q11-1: What kinds of psychological and psychiatric problems do thalidomide-impaired patients have?

Q11-2: Is there any connection between thalidomide impairment and autism?

Q11-3: Is epilepsy common in thalidomide-impaired people?

Q11-4: Are there any important points when meeting thalidomide-impaired people?