Management of Adult Turner Women in Japan

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Children’s Medical Center
Department of Pediatrics
Keinosuke Fujita
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1. Turner Society in Japan
2. Medical condition of adult Turner women: Data from Turner Society in Osaka and Tokyo
3. HEALTH CARE BOOK for Turner Women
The meeting in Copenhagen (1990)
The suggestion from Bente

1. Please inform about Turner syndrome to Turner girls and women.

2. Please establish Turner Society in Japan.
The first meeting of the family of Turner girls and women

Date: 23rd March, 1991
Place: Osaka City University Hospital
Members: 12 family
   2 parents, 9 mothers, 1 father
   No Turner girls or women
   3 doctors, 1 psychologist

The age of Turner girls and women of their parents: 7-24 years old
The home page of Turner Society
20 local Turner Societies in Japan at present
The petition to a minister of Health and Welfare about Growth Hormone therapy to Turner syndrome. 1998.12.16.
Medical condition of adult Turner women:
Data from Turner Society in Osaka and Tokyo

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National Center for Child Health
And Development
Material and Methods

- The members of Turner Societies in Tokyo and Osaka
- Turner women elder than 16 years old 152 persons
- Questionnaire returned by mail without person's name
- Answers from 83 women (52%)
Materials

Who answered:

TS women 65
Parents 18

Average age:

26 years old
Disclosure
who gave information

By Mother 60%
By Father 0%
By Doctor 28%
By myself 12%
The profile of two TS women without information

31 years old, unmarried
- answered by Mother
- Only GH therapy
- 143 cm
- Followed by Psychologist
- Amenorrhea
- Diabetes

34 years old, married
- answered by mother
- Only GH therapy
- 145 cm
- No follow up
- Amenorrhea
- No answer about complication
Body composition

- Mean height: 146.9 cm
  (Mean height of Japanese women: 158 cm)
  - With GH therapy: 148.4 cm (n=58)
  - Without GH therapy: 143.3 cm (n=18)
- Mean body weight: 47 kg
- Mean BMI: 21.9
- Mean West/height ratio: 68 cm

Diagram:
- Abdominal circumference/height ratio vs. BMI
  - $R^2 = 0.2718$
- Abdominal circumference/height distribution

GH (-) vs. GH (+)
Follow up doctors

Times visit clinic a year

No follow up

Pediatrics

Internal medicine

Obstetrics & Gynecology

Heart disease・Psychiatric

Ear, Nose, Throat

Other

Surgery

Other

小児科 産婦人科 内科 耳鼻咽喉科 心療内科・精神科 歯科 その他 未受診
Profile of TS women without follow up

16 years old
- unmarried
- answered by father
- Informed only short stature and GH
- Only GH therapy
- 140 cm
- polymenorrhea
- ECG, audiogram in 3 years

23 years old
- answered by TS woman herself
- Only GH therapy
- 140 cm
- Normal menstruation
- No examination for 3 years

34 years old
- Answered by mother
- Without information
- 145 cm
- Only GH therapy
- amenorrhea
## Recomendation

<table>
<thead>
<tr>
<th>Test</th>
<th>Frequency</th>
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<tbody>
<tr>
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<td>Bone Mineral Density</td>
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<td>Others (cholesterol)</td>
<td></td>
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</tbody>
</table>
Examination (n=83)

**Bone density**  achievement: 61%
- Not any examination: 23
- Not examine in 3 years: 9
- Examine in 3 years: 51

**Heart examination**  achievement: 48%
- Not any examination: 28
- Not examine in 3 years: 15
- Examine in 3 years: 40
  - MRI examination: 15% (n=13)

**Audiogram**  achievement: 41%
- Not any examination: 36
- Not examine in 3 years: 13

**Blood examination**  achievement: 88%
- Not examine in 1 year: 10
- Not examine in 3 years: 10

**Urinalysis**  achievement: 78%
- Not examine in 1 year: 18
- Not examine in 3 years: 15
Complications (multiple answers)

- Ovarian failure
- Osteoporosis
- Bone fracture
- Otitis media
- Hearing problems
- Metabolic syndrome
- Obesity
- Hypertension
- Diabetes
- Thyroid disease
- Psychiatric disease

Mean 1.5 times (1-2 times)
Bone Mineral Density

With estrogen medication

Without estrogen medication

BMD (gms/cm²)

年齢
Marriage/Pregnancy/Delivery

- married n=11 (no divorce)
- unmarried n=72
- No pregnant or deliver

We know one TS women who got Egg donation in US and had healthy Baby. She did not answered.
Conclusion

The members of Turner society are mainly twenties and thirties.
Many members are interested in their health.
Achievement rate was low in heart examination and audiogram.
Transition

Who should follow up adult TS women?
HEALTH CARE BOOK

健やかな毎日のために
The Japanese Society for Pediatric Endocrinology published this book for Turner women to keep examinations and control their health by themselves.
Complications

1. Obesity
2. Diabetes
3. Hypothyroidism
4. Liver disease
5. Anomaly of kidney
6. Cardiovascular disease
7. Otitis media, Hearing problems
8. Osteoploiosis
9. Orthodontics (矯正歯科)
10. Gynecology
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<thead>
<tr>
<th>チェック項目</th>
<th>チェックの間隔</th>
<th>2008年9月1日</th>
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<td>血圧測定</td>
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<tr>
<td>血糖・尿糖・ヘモグロビンA1c</td>
<td>随時血糖 120mg/dL 食後2時間尿糖（－） HbA1c 5.7%</td>
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<td>抗甲状腺抗体・甲状腺機能</td>
<td>6か月〜1年 に1度</td>
<td>FT4 1.4ng/dL TSH 1.50 μU/mL 抗TPO抗体 0.3u/mL以下 抗サイクリン抗体陰 1.5u/mL</td>
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<td>尿蛋白（±） 血清クレアチニン 0.9mg/dL 軽度腎盂拡大</td>
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<td>心エコー、MRI</td>
<td>1年、または、3年に1度**3</td>
<td>大動脈基部 30mm</td>
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<td>骨密度測定</td>
<td>3〜5年に1度</td>
<td>第2〜4腰椎 BMD 0.90g/cm²</td>
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<td>その他</td>
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<td></td>
<td>肥コレステロール 210mg/dL HDL-C 49mg/dL</td>
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※1 BMI = 体重(kg) / 身長(m)^2
※2 腎のうえで異常のない人でも一度は受ける。尿細管や尿路感染症のある人は定期的に受ける。
※3 生まれつき大動脈狭窄や大動脈剣弁弁の拡張がある人、大動脈剣弁狭窄の拡張がある人、高血圧のある人は、1年に1回心エコー。必要ならMRI。それらのない人は約3年に1度。
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This book was made for Turner women who finish Growth hormone therapy. You can use this book when Growth hormone finished or estrogen therapy started. You need your own health control for keeping healthy life. Do not forget your necessary examination.
Thank you.