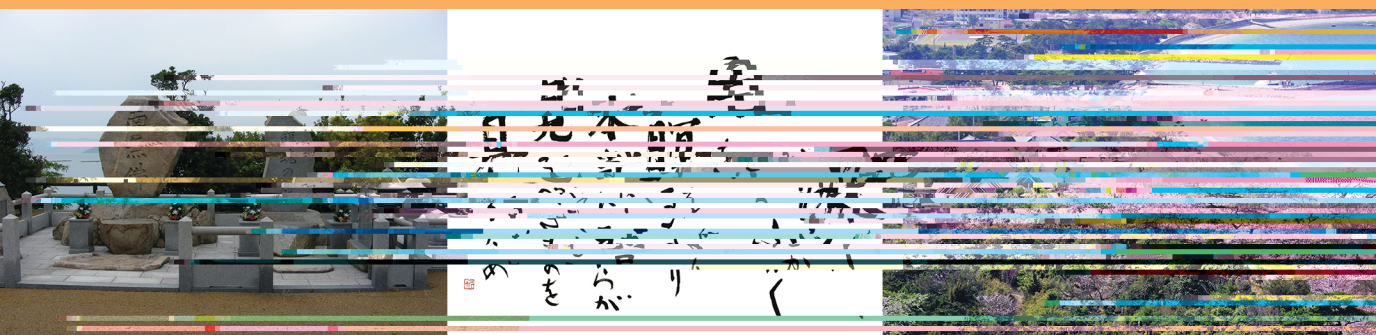


# Life Review of Aging Japanese Hansen's Disease Survivors

-Deeply *Deeply* Closing Our Eyes in Order  
to See What We Truly Should See



Makiko Kondo, Ph.D.

National Sanatorium Shima Seishoen



Horizon Research Publishing, USA





# **Life Review of Aging Japanese Hansen's Disease Survivors**

**- Deeply *Deeply* Closing Our Eyes in Order to See  
What We Truly Should See**

**Editorial Supervision**

**Makiko Kondo, Ph. D.**

Associate Professor, Graduate School of Health Sciences, Okayama  
University, 2-5-1 Shikata, Kita-ku, Okayama, 700-8558, Japan

E-mail: mkondo@cc.okayama-u.ac.jp

**Editor**

**National Sanatorium shima Seishoen**

6034-1, Aji, Takamatsu City,  
Kagawa Prefecture, 761-0198, Japan

Tel: +87 - 871-3131

Kazama shobo (Japanese Version)

Translation: Editage by Cactus Communications

**Horizon Research Publishing, USA**

**Title:** Life Review of Aging Japanese Hansen's Disease Survivors - Deeply  
*Deeply* Closing Our Eyes in Order to See What We Truly Should See

**Editorial Supervision:** Makiko Kondo, Ph. D.

**Editor:** National Sanatorium Shima Seishoen

**Publication Date:** February 28<sup>th</sup>, 2019

**Published by:**

Horizon Research Publishing  
2880 ZANKER RD STE 203  
SAN JOSE, CA 95134  
USA

<http://www.hrpub.org>

Printed on acid-free paper

**ISBN:** 978-1-943484-20-1

**Price:** \$70 per copy (USA)

**General Enquiries**

Publish with HRPUB, learn about our policies, submission guidelines etc.

Email: [book@hrpub.org](mailto:book@hrpub.org)

**Grant for Translation publication**

Japan Society for the Promotion of Science (JSPS)

<https://www.jsps.go.jp/english/index.html>

KAKENHI (Grant-in-Aid for Publication of Scientific Research Results)

Grant Number: 17HP6008

**Grant for the Project**

The Toyota Foundation

<https://www.toyotafound.or.jp/english/>

Research Grant Program in 2013

Grant Number: D13-R-0015

**Notice**

This book contains information obtained from authentic and highly regarded sources. Reprinted material is quoted with permission, and sources are indicated. A wide variety of references are listed. Reasonable efforts have been made to publish reliable data and information, but the author and the publisher cannot assume responsibility for the validity of all materials or for the consequences of their use.

**Trademark**

Product or corporate names may be trademarks or registered trademarks, and are used only for identification and explanation without intent to infringe.

**Copyright © 2019 Horizon Research Publishing Co., LTD**

This work is subject to copyright. All rights reserved. No part of this book may be reproduced or mitted in any form or by any means, electronic or mechanical, including photocopying, recording or by any information storage and retrieval system, without written permission from the author, except for the inclusion of brief quotations in a review.

## **Brief Introduction**

Telling the story of Hansen's disease to the children of the next generation.

How should society care for those who suffer from Hansen's disease and the related discrimination and prejudice? What are the relevant medical ethics? We listened to the life stories of nineteen Hansen's disease patients who survived the most extreme circumstances on an isolated island (shima) in the Seto Inland Sea. This book presents the lessons learned from the wisdom and negative history gleaned from their tragic lives.

<b>Contents</b>	<b>Page No.</b>
<b>For the Translated Edition (Makiko Kondo)</b> .....	1
<b>Frontispiece</b> .....	5
<b>Chapter 1. Significance of the Project</b> .....	17
I. Significance of the Project (Makiko Kondo) .....	19
II. Purpose of the Grant (Ryuta Oba) .....	37
III. Greeting from Natonal Sanatorium Oshima Seisho-en (Takahisa Yamamoto, Kazuo Mori, Hideyo Shinmori, Yoshiko Okano, Kyoko Tsukimori, Makiko Watanabe).....	38
<b>Chapter 2. The Story of Tatsuo   shima (Listener: Erika Miki)</b> .....	51
I. Diagnosis of Hansen’s Disease and Loss of Eyesight .....	54
II. Folk Remedies .....	58
III. Wife Was Cut off by Her Family .....	62
IV. Eldest Daughter Has Children and Becomes Ill.....	64
V. The Kindness of Other Survivors Inspired My Strength to Live.....	67
VI. Discrimination against Relatives Back at Home.....	77
<b>Chapter 3. The Story of Takahisa Yamamoto (Listener: Mikako Yamaberi)</b> .....	81
I. Troubled Times .....	86
II. Changing the Flow of Living.....	97
III. My Family .....	102
IV. Friend for Life (Ceramics); Glimmers of Love.....	114

V. Struggle and Improving Living Conditions.....	119
--	-----

## **Chapter 4. The Story of Hideko Sakata**

<b>(Listener: Maki Sanada)</b> .....	129
--------------------------------------	-----

I. Parents and Life at Home out of the Sunlight.....	133
--	-----

II. My Siblings.....	140
----------------------	-----

III. First Meeting with My Husband and the Way of Life at shima .....	149
---	-----

IV. Moving into a House on the Island .....	157
---	-----

V. Farm Work and Kidney Failure.....	160
--------------------------------------	-----

## **Chapter 5. The Story of Haruko Kawaguchi**

<b>(Listener: Mie Hachisuka)</b> .....	167
--	-----

I. Going to shima .....	170
-------------------------	-----

II. An ordinary life at shima .....	171
-------------------------------------	-----

III. A Happy Life.....	181
------------------------	-----

## **Chapter 6. The Story of K.Y (Listener: Kazuya gaki)**..... 185

I. Lived All Alone .....	187
--------------------------	-----

II. Happy I Came to shima .....	191
---------------------------------	-----

III. Life at shima.....	192
-------------------------	-----

IV. Current Situation .....	196
-----------------------------	-----

## **Chapter 7. The Story of Akihiro Kawakami**

<b>(Listener: Matsuko Kond )</b> .....	199
--	-----

I. Cannot Return until I am Only Ashes .....	203
--	-----

II. A Disease of Deterioration .....	207
--------------------------------------	-----

III. Separation from Blood Relatives .....	218
--	-----

IV. Trials and Tribulations of Hansen's Disease-affected Individuals .....	224
V. Life with My Wife.....	235
VI. Abolition of the Hansen's Disease Prevention Law; the National Redress Suit .....	243
VII. Lived for Too Long .....	249
<b>Chapter 8. The Story of Shigenobu Morikawa</b> <b>(Listener: Mie Fujikawa)</b> .....	259
I. Gave up on My Dreams .....	261
II. Life at shima .....	264
<b>Chapter 9. The Story of Kiyoe Tamura</b> <b>(Listenter: Tamiko Kubo)</b> .....	269
I. The Suffering of my Family (From Contracting the Disease until Entering the Sanatorium) .....	274
II. Life at shima before and after the Pacific War .....	291
III. Marriage and Living Together with My Husband.....	302
IV. Return to My Hometown .....	332
<b>Chapter 10. The Story of Yoshimi chi</b> <b>(Listener: Kimi Ozaki)</b> .....	337
I. Went to shima; Intended to Stay Only a Week .....	340
II. Disease Worsened.....	343
III. My Lifestyle at the Time .....	349
IV. Current Lifestyle (Free and Satisfied Life, Interactions without Discrimination).....	356

<b>Chapter 11. The Story of Mutsuko Wakibayashi</b> <b>(Listener: Mitsuno Kond )</b> .....	367
I. Forced from My Hometown and Went to the Shikoku Pilgrimage Route....	371
II. Promin Therapy and Painful Symptoms.....	388
III. Life at shima.....	392
IV. Looking Back at 64 Years Living on shima.....	399
<b>Chapter 12. The Story of Emiko nishi</b> <b>(Listener: Misae Satachi)</b> .....	405
I. My Blood Relatives .....	408
II. Life at shima .....	416
III. Things Worth Living for .....	424
IV. Current Life and the Future.....	433
<b>Chapter 13. The Story of Kiyoko Tada</b> <b>(Listener: Mai Konishi)</b> .....	443
I. My Mother Contracted the Disease and Was Forcibly Interned.....	447
II. Contracting the Disease .....	452
III. My Husband .....	454
IV. Life at shima.....	460
V. Visiting the Family Grave for the First Time in Decades .....	462
<b>Chapter 14. The Story of Yasunaga no</b> <b>(Listener: Chiyo Kawasome)</b> .....	471
I. Contracting the Disease .....	473



II. Coming to shima.....	474
--------------------------	-----

III. Coming and Going between the Outside World and shima .....	476
---	-----

## **Chapter 15. The Story of Kayo Hiratsuka**

<b>(Listener: Tomoko Sato)</b> .....	485
--------------------------------------	-----

I. Separated from my mother at the age of seven .....	488
---	-----

II. Raised in the Young Women's Room and Became Independent.....	491
--	-----

III. Treatment .....	495
----------------------	-----

IV. Entertainment on the Island .....	499
---------------------------------------	-----

V. My Current Life.....	504
-------------------------	-----

## **Chapter 16. The Story of Kazuo Mori**

<b>(Listener: Kikaru Hichikuro)</b> .....	507
---	-----

I. From Contracting the Disease to Entering the Sanatorium.....	509
---	-----

II. My Elementary School Years.....	512
-------------------------------------	-----

III. Going to High School (Combining Disease and Study).....	515
--	-----

IV. The Doctors.....	523
----------------------	-----

## **Chapter 17. The Story of Tsuneji Isono (Listeners/Editors:**

**Manami Ito, Mana Hashimoto, Ayumi Fujiwara, Haruka**

<b>Yoshinari, Takeshi Okamoto)</b> .....	525
--	-----

I. My Mother, Who Had Sons and a Husband Taken by War or Hansen's Disease, Cried as She Sent Me off.....	529
---	-----

II. In Hindsight, Life in the Young Men's Dormitory Provided Fond Memories .....	537
---	-----

III. During the War, the Number of Interned Patients Increased, and Due to the Lack of Materials and Personnel, We Were Forced into a Meager Lifestyle .....	541
--	-----

IV. It Was Hard to Endure an Eye Excision done for Research Purposes; Promin was Effective .....	545
V. Since There Was a System of Mutual Assistance, Even People Who Were Physically Disabled Would Help Each Other to Keep Living .	548
VI. Times Changed, and I Feel Content with My Current Life .....	551

**Chapter 18. The Story of Teruichi Baba  
(Listener: Atsuko Nakayama) ..... 557**

I. Contracting the Disease and My Lifestyle When Entering the Sanatorium .	559
II. After the Abolition of the Hansen's Disease Prevention Law .....	565

**Chapter 19. The Story of Hanako Kadowaki  
(Listener: Mika Seo) ..... 571**

I. From Contracting the Disease to Deciding to Enter the Sanatorium (Painful Life in My Hometown).....	574
II. To shima .....	582
III. Worsening Condition and Health Examinations .....	590
IV. The Hansen's Disease Prevention Law, a Bad Law.....	595
V. Life without My Eyes.....	603

**Chapter 20. The Story of Hisao Honda  
(Listener: Toshitsugu Fujimoto) ..... 609**

I. From Contracting the Disease to Entering the Sanatorium.....	615
II. Life after Entering the Sanatorium .....	623
III. Abolition of the Hansen's Disease Prevention Act and the National Redress Suit .....	630
IV. Long Relationships with Friends off the Island .....	632
V. Worries about the Future of shima .....	637

VI. Surgery for Aftereffects .....	640
VII. Looking Back at My Life.....	645
<b>Chapter 21. Impressions from the Nurses</b>	
<b>Who Listened to the Life Reviews .....</b>	<b>653</b>
I. Impressions from the Nurses after Listening to the Stories .....	655
II. Impressions from the Assistant Chief Nurses	
Who Coordinated the Nurses .....	676
<b>Chapter 22. Sequence of Events of the Project and Changes</b>	
<b>Caused by Performing the Life Reviews (Yoshiko Amano) .....</b>	<b>681</b>
<b>Chapter 23. Contributions after Publication of the Japanese</b>	
<b>Edition.....</b>	<b>693</b>
I. Rev. Sh ken Tokiwa, Who Served as a Bridge between Blind Hansen's	
Disease-affected Individuals and Society at Large during the Period of	
the Hansen's Disease Prevention Law (Sh han Tokiwa).....	695
II. In Memory of Ms. Hanako Kadowaki (Akika Kondo, Takuo Kaneko) .....	700
III. shima Seishoen and the Takamatsu Recitation Association	
(Takao Hasui).....	704
IV. Care Needed at the Sanatorium Today after Receiving Assistance from	
the Toyota Foundation (Makiko Kondo, Akemi Doi, Makiko Watanabe,	
Chie Munetomo) .....	713
V. Instead of a Book Review,	
"Reflections of One Physician on Public Health" (Takeo ta).....	728
<b>Chapter 24. Basic Knowledge of Hansen's Disease.....</b>	<b>737</b>
I. Pathophysiology of Hansen's Disease (Makiko Kond ) .....	739
II. History of Hansen's Disease (Taeko Miura) .....	764

## Contents

III. Current Dtate of the National Sanatorium   shima Seishoen (Kazue Ishikawa).....	787
IV. Conceptualization of the Future of the National Sanatorium   shima Seishoen and Upcoming Issues (Ky   ko Tsukimori) .....	807

## For the Translated Edition

**Makiko Kond**

Graduate School of Health Sciences, Okayama University

*Telling the story of Hansen's disease to the children of the next generation.*

*How should society care for those who suffer from Hansen's disease and its related discrimination and prejudice? What are the relevant medical ethics? We listened to the life stories of 19 Hansen's disease patients who survived the most*

*This book presents the lessons learned from the wisdom and negative history gleaned from their tragic lives.*

This book contains the life stories of 19 Hansen's disease survivors who spent their lives at a Hansen's disease sanatorium called the National Sanatorium Shima Seishoen (in Japan).

Around the world, Hansen's disease has been stigmatized and the subject of prejudice and discrimination since antiquity due to the changes in appearance it causes. Until the discovery of the magic bullet drug, Promin, the disease could not be suppressed. In addition, when the causative bacteria were discovered, the plan for safeguarding society, from the perspectives of bacteriology and public health, was through isolation.

The characteristics of Hansen's disease in Japan include the following: 1) the inhumane treatment of Hansen's disease-affected individuals progressed in the era of the crisis for national survival after defeat in WWII, 2) even after the discovery of the magic bullet drug, the abolishment of the Leprosy Prevention Law was delayed, and thus many survivors who had missed their chance to return to society had to spend their entire lives at sanatoria, and 3) the eradication of Hansen's disease was sought through lifelong isolation and sterilization, and thus survivors who were not given the chance to raise children are now elderly, and the history of Japan's Hansen's disease sanatoria will perish with the deaths of the survivors.

These stories from Hansen's disease survivors, who have lived through extreme circumstances, are unique in that they can only be told by someone who had the experiences they did, and thus can be considered part of the shared heritage of all humanity. In order to never repeat the cruel lifestyle of the past as described by Hansen's disease survivors, their stories must be passed down, and we must think deeply about human dignity and medical ethics based on their experiences. In addition, just like existential psychology was born in Auschwitz, the stories of these survivors contain wisdom and human strength that are unique to survivors who have overcome great adversity to reach old age. Now that the average age of

## Frontispiece

### I. Images from shima during the Strict Quarantine Policy



Patients seine fishing at a beach  
(September 1946)



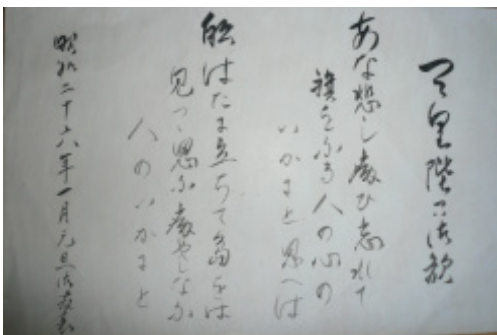
Children admitted to the facility (boys)



Children admitted to the facility



The Showa Emperor's visit to shima



Poem by Emperor Showa (Hirohito)

‘Ana kanashi, yamai wasurete hata-wo  
furu, hito no kokoro-no ikani to omoeba’

“How said it is  
to think of the hearts of those who  
wave their flags for me,  
forgetting their illness”

‘Funa-bata-ni, tachite shima-woba  
mitsutsu omou, yamai yashinau hito-no  
ikani-to’

“I tarry on the deck of the ship as I  
look at shima  
and think of the hardships  
of those who tend to the sick.  
Unveiled New Year's Day, 1951

# **Chapter 1. Significance of the Project**

## **I. Significance of the Project (Makiko Kondo)**

1.



## **Chapter 24. Basic Knowledge of Hansen's Disease**

**I. Pathophysiology of Hansen's Disease (Makiko Kond )**

**II. History of Hansen's Disease (Taeko Miura)**

**III. Current State of the National Sanatorium shima Seishoen  
(Kazue Ishikawa)**

**IV. Conceptualization of the Future of the National Sanatorium  
shima Seishoen and Upcoming Issues (Ky ko Tsukimori)**

# I . Pathophysiology of Hansen's disease

**Makiko Kond**

Graduate School of Health Sciences, Okayama University

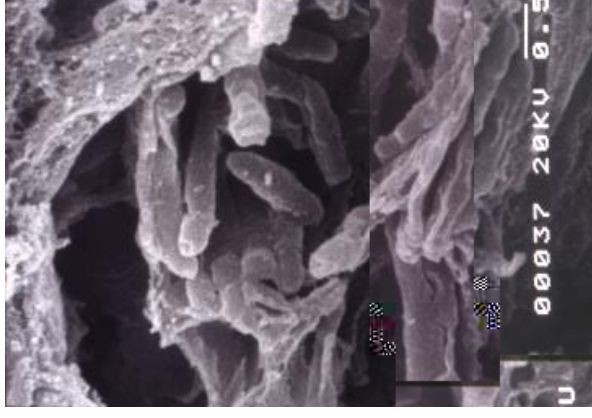


# What is Hansen's disease?

It is a chronic granulomatous inflammatory condition caused by the leprosy bacillus (*Mycobacterium leprae*).



Armauer Hansen discovered the leprosy bacillus in 1873



Leprosy bacillus imaged using a scanning electron microscope from the footpad of a nude mouse (Image source: Dr. Masanori Matsuoka of the Leprosy Research Center at the National Institute of Infectious Diseases)

# Characteristics of infection with the leprosy bacillus (*Mycobacterium leprae*) (1)

◇ The optimum temperature for *M. leprae* is 30-33°C (lower than body temperature)

It proliferates in the peripheral nerves and mucosa near the surface (ends of the hands and feet, head, face, nose, eyes, and ears).

\* Since the core temperature of the body is higher at the vital organs necessary for maintaining life (liver, kidneys, pancreas, etc.), they do not proliferate there. Thus, deaths due to organ failure are rare (excluding acute aggravation from the leprosy reaction, weakness around the time of the Pacific War, and the like)

- The parts of the body that are most visible are affected by lesions
- Affected individuals must continue to live through their changes in appearance.

### **Makiko KONDO: Biography**

Dr. Makiko Kondo obtained Bachelor of Education and Registered Nurse degrees from Tokushima University in 1989, a Master of Science in Nursing degree from Chiba University in 2000, and a Doctor of Philosophy in Nursing from Osaka Prefecture University at 2007. Currently, she is an associate professor at the Graduate School of Health Sciences in Okayama University. She teaches doctor's course, master's course (Oncology Certified Nurse Specialist), and undergraduate. Her field of expertise is qualitative studies and building of new principles and theory, and her research themes involve bioethics and life review of Hansen's disease survivor had experienced extreme state, care for parents with cancer and their children, nurses' grief care, and conceptualization of clinical nursing competency.



## Brief Introduction

Telling the story of Hansen's disease to the children of the next generation.

How should society care for those who suffer from Hansen's disease and the related discrimination and prejudice? What are the relevant medical ethics? We listened to the life stories of nineteen Hansen's disease patients who survived the most extreme circumstances on an isolated island (Oshima) in the Seto Inland Sea. This book presents the lessons learned from the wisdom and negative history gleaned from their tragic lives.

**Makiko KONDO, Ph.D.**

Graduate School of Health Sciences

Okayama University

2-5-1 Shikata, Kita-ku, Okayama, 700-8558, Japan

E-mail: makondo@cc.okayama-u.ac.jp

National Sanatorium Oshima Seishoen

6034-1, Aji, Takamatsu City,

Kagawa Prefecture, 761-0198, Japan

Tel: +81- 87-871-3131

ISBN 978-1-943484-20-1



[www.hipub.org](http://www.hipub.org)

\$ 70.00 USA