

April 2013

To the press and whom it may concern

Announcement

**“Questionnaire Survey on the Financial Burden of Fertility Treatment Part 2”  
Analysis based on the voices of 1,993 respondents, the  
number overwhelming the previous survey!**

NPO Fine (Fertility Information Network)

<http://j-fine.jp/>

NPO Fine is a self-support group for infertility patients and those who are suffering from infertility by the people who have had the experience of infertility. Fine carried out the “Questionnaire Survey on the Financial Burden of Fertility Treatment Part 2.” Based on the voices of 1,993 respondents, the number which overwhelms the previous questionnaire survey Part 1 conducted in 2010 (1,111), Fine announces the survey results.

#### Survey objectives

Japan's total fertility rate is 1.39 (\* 1) and we hear the news on declining birthrate due to late marriage and childbirth everyday. While measures to promote child birth and child caring, such as establishments of nurseries and reduced work hours, are urgently needed, there are people who are suffering from infertility even though they are willing to as the research data showed (\*2) that 1 in 6 couples received fertility treatment or the test.

Although "infertility" and "fertility treatment" are more widely recognized compared to the past, the actual situation is still unknown.

This research was conducted to clarify the current situation focusing on the “financial burden” of infertility, which was delved deeper by comparing with the research conducted 3 years ago.

In addition, as a supporting system to reduce the economic burden of fertility treatment such as in vitro fertilization (IVF) and micro fertilization, the Subsidy Program for Specific Fertility Treatments subsidizes a part of the medical cost uncovered by health insurance. It was partially reduced from JPY 150,000 to JPY 75,000 in April 2013. As the reduction was announced during the survey period, questions were added to gather opinions on the matter.

The actual situation surrounding the respondents clarified in this research shall be disseminated for educational purpose on infertility and lobbying the government as materials for the submission of our 6th petition to the Diet and the demand statements.

We sincerely request that the survey results are featured by your medium for raising awareness in society at large.

#### Survey method

Setting the questionnaire form on NPO Fine’s website. After announcement to a wider population, including Fine members, as well as former infertility patients, the research gained 1,993 valid responses.

#### Questionnaire survey period

December 28, 2012 - March 10, 2013

#### Outline of questions

The questionnaire survey of 38 questions comprised 20 questions addressing the present situation of fertility treatment and economic burden, 10 questions on the Subsidy Program for Specific Fertility Treatments and 8 questions on attributes of the respondents. The questionnaire adopted multiple-choice and open-ended questions. As the percentages in the texts and graphs are calculated by rounding a number with 2 decimal places, there may be a slight gap.

■ Profile of respondents

**Q28:** What is your age and sex?

The result showed 13 respondents (0.6%) were “Below 25 years old,” 197 (9.9%) were “25-29 years old,” 544 (27.3%) were “30-34 years old,” 739 (37.1%) were “35 to 39 years old,” 419 (21.0%) were “40 to 44 years old” and 81 (4.1%) were “45+ years old.” Respondents in their 30’s accounted for a majority at 64.4%, which was followed by “40-44 years old.” In the previous research, respondents in their 20s accounted for 12.2%, the 30s for 71.3% and the 40s and above for 16.2%. The result showed the overall age has been raised. In this research, 1 in 4 was in their 40s and women accounted for over 99% (1,981).

**Q31:** How long was the treatment period?

The largest number of respondents for the question was 861 (43.2%) for “2-4 years,” which was followed by 544 (27.3%) for “1 year to less than 2 years,” the third was 295 (14.8%) for “Less than 1 year,” and 268 (13.4%) for “5-9 years.”

**Q2:** Which treatment are you receiving now?

With the multiple answers, the largest number of respondents was 587 (29.5%) for “Not treated,” which was followed by 532 (26.7%) for “Micro fertilization,” 491 (24.6%) for “In vitro fertilization,” 255 (12.8%) for “Artificial insemination,” and 239 (12.0%) for “Timing method.” Of these, micro fertilization and in vitro fertilization (IVF) are within the scope of the Subsidy Program for Specific Fertility Treatments.

■ Treatment cost

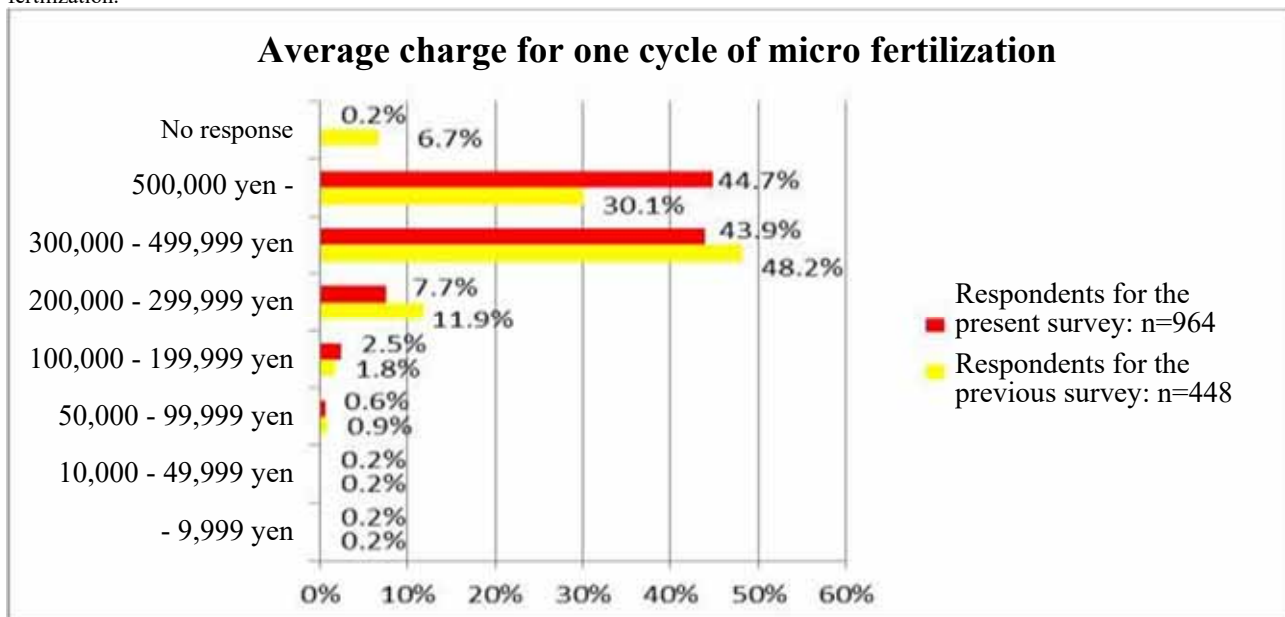
**Q3-2:** What is the average charge for one cycle of IVF?

Of 1,083 respondents, the largest number of respondents was 565 (52.2%) for “300,000 - 499,999 yen,” which was followed by 291 (26.9%) for “500,000 yen - ” and 157 (14.5%) for “200,000 - 299,999 yen.” In the case of micro fertilization, the distribution changes as follows (see Q3-3).

**Q3-3:** What is the average charge for one cycle of micro fertilization?

Of 964 respondents, the largest number of respondents was 431 (44.7%) for “500,000 yen - ,” which was followed by 423 (43.9%) for “300,000 - 499,999 yen.” As shown in the graph, the treatment cost has increased since the previous survey. Micro fertilization in Japan accounts for 37.4% (\*3) of ART (Note 1).

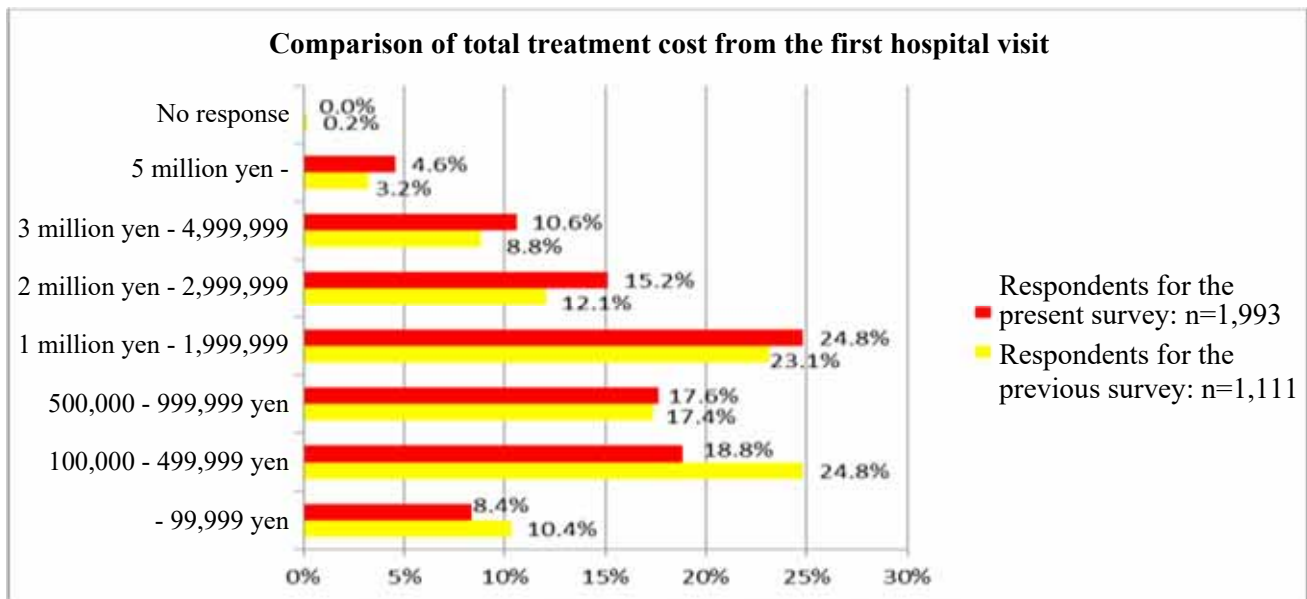
[Note 1] ART(Assisted Reproductive Technology) : Assisted reproductive or advanced reproductive medical care, such as IVF and micro fertilization.



\*The graph shows the ratio when the number of respondents is

**Q6:** What is the total cost of treatment since the start of hospital visit?

The largest number of respondents for the question was 495 (24.8%) for “1 million - 1,999,999 yen,” which was followed by 375 (18.8%) for “100,000 - 499,999 yen” and 352 (17.6%) for “500,000 - 999,999 yen.” Compared to the previous survey, all categories for not less than 500,000 yen increased, and those for not less than 1 million yen accounted for a majority with 55.1% (1,099), increasing from the previous survey with 47.3% (525).



\*The graph shows the ratio when the number of respondents is 100.

**Q7:** Have you ever felt hesitant or postponed the next step treatment due to a financial reason?

There were 1,614 respondents (81.0%) who felt hesitant or postponed the next step treatment due to a financial reason, combining “Very often” (983) and “Quite often” (631). Those who answered “Not often” and “Not at all” totaled 358 (18.0%). There were voices that “Micro fertilization has been treated from the beginning,” so there was no option and “Timing method is an ongoing treatment, but may feel hesitant in the future.”

**Financial burden of non-treatment cost**

Some infertility patients may not have the right clinic near their homes and may have to travel a long distance, causing to incur a large amount of transportation and accommodation costs. There are some who combine alternative healthcare.

**Q4-1:** What is the average transportation cost for one cycle of hospital visits?

Number of respondents was 1,641 (82.3%) and 4 out of 5 answered there is a burden of transportation cost. The largest number of respondents was 662 (40.3%) for “1,000 - 4,999 yen,” which was followed by 371 (22.6%) for “5,000 - 9,999 yen” and 278 (16.9%) for “10,000 - 20,000 yen.” There were 196 (11.9%) who answered “20,000 yen - , suggesting a long-distance and high frequency of outpatient treatments.

**Q5-2:** What is the average accommodation cost for one cycle of hospital visits?

Number of respondents was 227, showing 11.4% of respondents have received treatment requiring accommodation. The largest number of respondents was 36 for “10,000 - 19,999 yen,” which was followed by 27 for “5,000 - 9,999 yen” and 22 for “20,000 - 30,000 yen.”

**Q18 :** How much is spent on alternative healthcare other than the fertility treatment per month (multiple

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answers)?

The largest number of respondents was 1,231 (61.8%) for “Supplement and health foods,” spending monthly average of 7,204 yen, which was followed by 556 (27.9%) for “acupuncture” spending 17,719 yen, 490 (24.6%) for “Chinese medicine (covered by insurance)” spending 4,284 yen, 424 (21.3%) for “Chinese medicine (not covered by insurance)” spending 21,245 yen, and 343 (17.2%) for “Chiropractic” spending 12,477 yen. In the previous survey, it was in the order of “Supplement and health foods,” “Chinese medicine (covered by insurance),” “Chinese medicine (not covered by insurance),” “acupuncture” and “Chiropractic.”

### ■ Balancing work, etc. and treatment

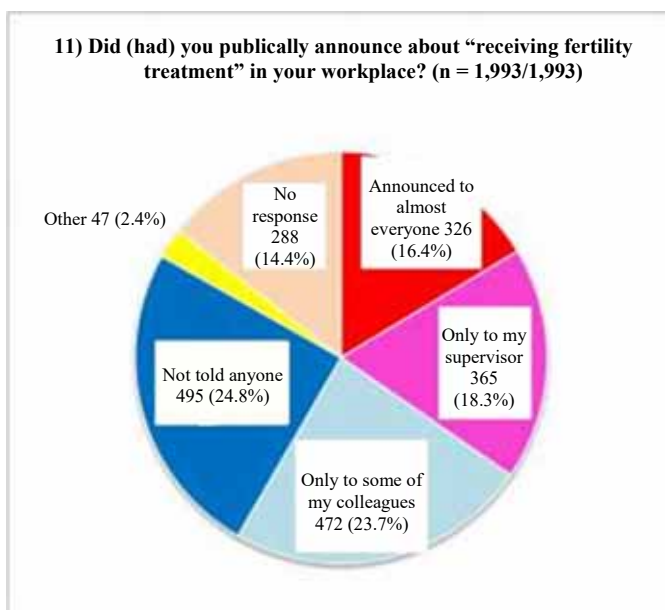
#### **Q14:** Has the treatment ever hindered work or other plans?

There were 1,725 respondents (86.6%) who answered that the treatment did hinder work or other plans, combining “Very often” (982) and “Quite often” (743). Those who answered “Not often” and “Not at all” totaled 246 (12.3%), demonstrating extremely large number of respondents were hindered by the treatment. There were voices that “Balancing work and treatment has been extremely difficult,” “Time management has been hard,” and many other compelling comments. With IVF and micro fertilization treatment, patients are often required to visit a medical institution on a consecutive days for injection and inspection, or a date of egg collection (Note 2) is designated at the last minute, so many voiced concerns for “not being able to plan ahead” and “difficulty in work arrangement.”

[Note 2] Egg collection: Recovering matured eggs from the ovaries. Generally, an ovulation inducing agent is used to stimulate the ovaries to collect multiple eggs. In this regard, however, if there is no mature egg to be collected, or even if it is collected, the condition is not up to fertilization, the treatment is discontinued.

#### **Q11:** Do (did) you talk about “receiving fertility treatment” in your workplace?

The largest number of respondents was 495 (24.8%) for “Not told anyone,” which was followed by 472 (23.7%) for “Only to some of my colleagues,” 365 (18.3%) for “Only to my supervisor,” and just 326 (16.4%) for “Announced to everyone.” The result showed 1 in 4 has “Not told anyone,” demonstrating a hard reality that it is difficult to announce about the treatment. The reasons for the difficulty are that “it may affect the renewal of my temporary contract,” “many women at my workplace are still not married or have no child,” “even though I am a medical professional, my workplace did not show any understanding,” “there is prejudice against fertility treatment,” “in my previous workplace, I received a malice comment,” and so forth.



#### **Q13:** Is there any support for the fertility treatment by your workplace?

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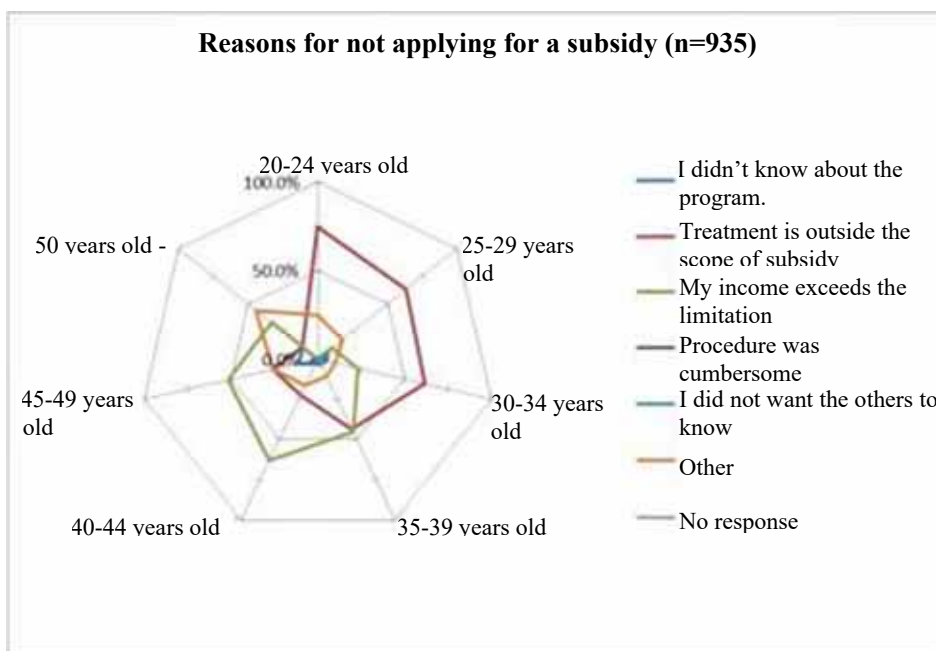
404 (20.3%) of respondents answered “Yes” and 1,272 (63.8%) answered “No.” Those who answered “Yes” commented the company allowed “to leave early and take an annual holiday in the last minute,” “my colleagues supported me in work” and others. The result that 1 in 5 answered “there is support,” evidencing improvement in understanding and support for fertility treatment in workplace, is a promising sign for those who are concerned about balancing treatment and work. On the other hand, many of those who answered “No” requested for support to continue treatment and work. In addition, many suggested “flexible work schedule and reduced work hours,” “a half-day holiday and work in afternoon,” and “use of paid holidays by the hour” as solutions to the current situation.

### ■ Subsidy Program for Specific Fertility Treatments

It is a program started in FY2004 by the MHLW in support of couples who are suffering from infertility, and has been implemented since FY2005 in designated and focal cities in all prefectures. The program grants 150,000 yen per treatment for one fiscal year up to 2 treatments for accumulation of up to 5 years. Implementing bodies are the governments of designated and focal cities, to whom the MHLW subsidizes the program cost. The subsidy for some treatments was reduced from JPY 150,000 to JPY 75,000 in April 2013.

#### **Q20/21:** Did you know about the subsidy program? Have you ever applied for a subsidy?

For Q20, 1,742 (87.4%) answered that they “Know well” and “Know” about the Subsidy Program for Specific Fertility Treatments and 39 (2.0%) answered “Did not know.” The recognition has increased by 7.7 points since the last survey. For Q21, 1,026 (51.5%) answered “Yes” and 935 (46.9%) answered “No” about the application for a subsidy. Those who have applied for a subsidy have increased by 11.2 points since the last survey. The reasons for those who answered “No” included “my treatment is outside the scope of the subsidy,” “I am planning to apply,” and “my income exceeds the limit amount.” The following graph shows the reasons by age.



The graph shows there are many who are 40+ years old and cannot apply for a subsidy due to the income limitation, and who are less than 35 years old and are treated outside the scope of the subsidy. The reasons for not applying for a subsidy vary by age.

#### **Q37:** What are the average cost of treatment and medicines in the “past case of transplanting a frozen embryo (Note 2)”?

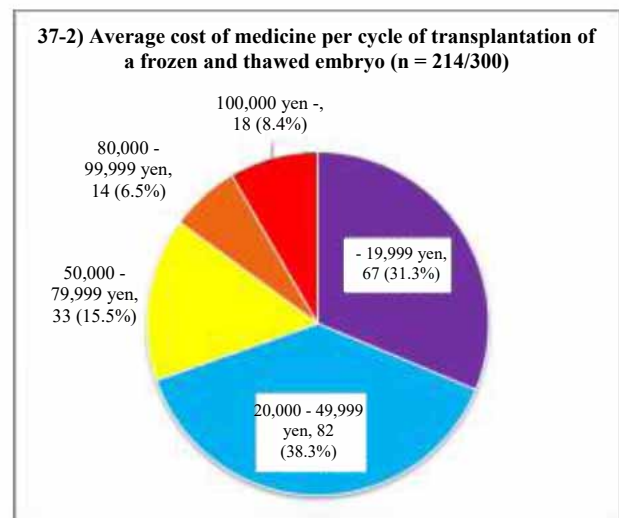
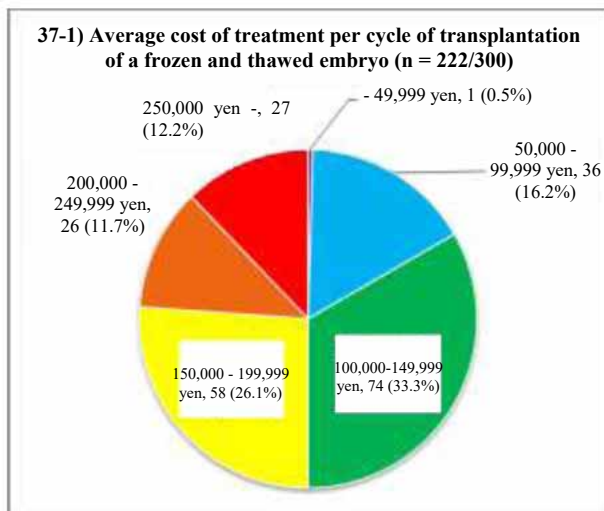
In April 2013, the Subsidy Program for Specific Fertility Treatments reduced the amount from 150,000 yen to 75,000 yen for the treatments of (1) "transplantation of a frozen and thawed embryo (Note 3)" and (2) the case of “discontinuation of treatment as eggs cannot be recovered or condition of collected eggs are not up to

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fertilization after an attempt to collect eggs (See Note 2).”

For the question on the average cost of treatment for "transplantation of a frozen and thawed embryo," 300 respondents answered. The largest number of respondents was 74 (24.7%) for "100,000 - 149,999 yen," which was followed by 58 (19.3%) for "150,000 - 199,999 yen" and 36 (12.0%) for "50,000 - 99,999 yen." Those who spent not less than 100,000 yen accounted for 61.7% with the cost exceeding the current subsidy amount of 75,000 yen. In many cases, ovulation is stimulated by medicine in the forms of pills, injections or patches. The largest number of respondents on these costs was 82 (27.3%) for "20,000 - 49,999 yen," which was followed by 67 (22.3%) for "- 19,999 yen" and 33 (11.0%) for "50,000 - 79,999 yen."

[Note 3] Transplantation of a frozen and thawed embryo: A treatment where an embryo (fertilized egg) produced by IVF or micro fertilization is frozen, stored, thawed at a cycle different from the ovum collection, and transplanted in the uterus.



### Findings from the survey results

Number of children who are born by ART (See Note 1) was 28,945 in 2010 and shows that approximately 1 in 37 live births is born by ART. Furthermore, live births by ART accumulate to over 270,000 in Japan. In this respect, ART is no longer a rare treatment and many couples are blessed with a child by ART.

While the topic of infertility is often taken up by the media, it is true to say the accurate knowledge about the fertility treatment has not yet penetrated society.

To prove this, although the questionnaire survey focused on the economical burden, many commented not just financial aspects, but on the hardships about time management for hospital visits and balancing with work, anxiety for unsuccessful treatment, concerns for not receiving any support from their colleagues and others. The survey highlighted diverse non-financial burdens.

\*Some comments are introduced here.

- As I cannot continue the treatment with out my job (to pay for the cost), I will have to continue working even though I can't walk with my head high.
- I have been making my best efforts to be blessed with a child, but I am seriously stressed about not succeeding for many years, as well as the financial burden.
- As fertility treatment is extremely stressful without any promise, it would relieve me if at least a financial concern is removed.
- I am finding difficulty in my work arrangement as the plans for egg collection and transplantation are informed only a few days in advance.
- I had 1 year of temporary retirement to concentrate on the treatment, but returned to office as the treatment cost was high.
- As my husband's income is not enough, we have borrowed money from both of our parents.

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- I am being treated because I want a child, but I worry about prejudice even if I am blessed with a child. I myself used to think “how can anyone have a child artificially?” without even any knowledge of the treatment.
  - I requested my supervisor to reduce my workload for the fertility treatment, which was not accepted and I was recommended to retire instead.
  - I have borrowed money from a consumer finance company.
  - Actually, I am now thinking whether I should retire and concentrate on the treatment.
  - Just for the sake of having a child, I am desperately making ends meet by reducing the cost of living to somehow squeeze out the cost of treatment.
- \* Some comments on “reduction of subsidies in the Subsidy Program for Specific Fertility Treatments” are introduced here.
- After learning about the Subsidy Program, I decided to move onto the advanced fertility treatment. Without the Program, I probably gave up on having a child.
  - With the ART, I was blessed with my first child. With a reduction in the subsidy amount, the financial burden will become significant and I will have to give up on my second child for a financial reason.
  - As the subsidy is paid from taxes, I was so grateful for applying.
  - There are some who give up on the fertility treatment due to a heavy financial burden. Please re-consider the reduction of a subsidy amount.
  - By this reduction of the subsidy, a hurdle for the fertility treatment is further raised.
  - Encouraged by a tangible support such as the subsidy, I am trying the treatment.

The present survey showed that “various concerns of the respondents have not changed from the previous survey 3 years ago” regarding the burden of high treatment cost, balance between the treatment and work, relation with their colleagues and others and the future life plan. First, it is essential that these realities are correctly understood.

Infertility, suffered by 1 in 6 couples, is now by no means uncommon and anyone closed to you may be suffering secretly. We believe it is important that others correctly understand the infertility and present situation of fertility treatment and deepen their understanding as requirements to support those who are suffering from infertility. Again, we sincerely request that the research results are featured by your medium for raising awareness of society at large.

There are more intriguing results from other numerous questions.

The results will also be released on our website in the near future. For inquiries and opinions regarding the research results, please feel free to contact the following.

\*1: MHLW, “Total Fertility Rate”

[http://www.mhlw.go.jp/toukei/saikin/hw/jinkou/kakutei11/dl/14\\_tfr.pdf](http://www.mhlw.go.jp/toukei/saikin/hw/jinkou/kakutei11/dl/14_tfr.pdf)

\*2: National Institute of Population and Social Security Research, “The 14th Basic Research on Childbirths” and “Overview of Nationwide Survey on Marriage and Child Birth and Families”

<http://www.ipss.go.jp/ps-doukou/j/doukou14/doukou14.asp>

\*3: Japan Society of Obstetrics and Gynecology, “FY2011 Ethics Committee Registration and Investigation Subcommittee Report (Acta Obstetrica et Gynaecologica Japonica, Journal 64, Volume 9)”

<http://plaza.umin.ac.jp/~jsog-art/report2010.pdf>

\*4: Japan Society of Obstetrics and Gynecology, “Changes in Treatment Cycles and Live Births from 1985 to 2010”

<http://plaza.umin.ac.jp/~jsog-art/20121017data1.pdf>

\* Please access the following URL for complete questions of the present questionnaire survey.

<http://j-fine.jp/cgi-bin/mail/mail.cgi?id=keizai>

\* Please access the following URL for the questions and results of the previous questionnaire survey.

Questions: <http://j-fine.jp/top/anke/keizai.html>

Results: <http://j-fine.jp/top/anke/keizai-anke.html>

#### □ Future activities of NPO Fine (excerpt) (as of April 10, 2013)

**First time in Japan! Join our “Infertility Peer Counselor Training Course” available by e-learning!**

For the first time in Japan, we are training Infertility Peer Counselor specialized on infertility. Courses have been opened for the nine consecutive years since 2005.

“One-year Crash Course for License” has been specially opened which allows to acquire a license in 1 year. Campaigning now! (until June 30)

\*Reference: <http://j-fine.jp/e-pia/index.html>

**First in Japan! As an advocacy organization for people who are suffering from infertility, we have submitted petitions to the Diet!**

*NPO Fine is an advocacy organization that supports persons with infertility experience in the past, present and future.*

For the first time as an advocacy organization representing people who are suffering from infertility, seeking to reduce the economic burden of infertility patients, we submitted our first petition to the Diet in 2007. In May 2011, the fourth petition to the Diet, signed by approximately 20,500 people, was adopted by the House of Representatives for the first time and sent to the Cabinet. We are now gathering your signatures for the sixth petition to the Diet in May 2013!

\*Reference: <http://j-fine.jp/shomei/shomei.html>

#### **Submission of various demand papers**

We have submitted to the MHLW various demand papers on approval of new drugs, additional indication of insurance coverage, self-injection, re-consideration for the reduction in the Subsidy Program for Specific Fertility Treatments, and others.

\*Reference: <http://j-fine.jp/activity/act/index.html>

#### **Media (Interviews, etc.)**

Asahi Shimbun, Yomiuri Shimbun, Mainichi Shimbun, Nihon Keizai Shimbun, Sankei Shimbun, Hokkaido Shimbun, Tokyo Shimbun, Chunichi Shimbun, Kyoto Shimbun, Nishinippon Shimbun, Kumamoto Nichinichi Shimbun, and others, NHK "Close-up Gendai," "Metropolitan Area Networks," NTV "Today's Event," Nippon TV G+ "Healthcare Renaissance," Fuji TV news program, "Mr. Sunday," and others, TBS TV "Hanamaru Market," and others, "Weekly Asahi," "I Want a Baby," "AERA," "Domani," "Fujinkoron," "Weekly Gendai," "Weekly Bunshun," "GLOW," and others.

- Number of Fine members is approximately 1,300 and we have started the SNS!

Number of registrants: Approximately 1,300 (as of April 2013) -

<p><b>NPO Fine</b>                      <a href="http://j-fine.jp/">http://j-fine.jp/</a> <b>6-11-5-201, Kiba, Koto-ku, Tokyo, 135-0042</b>    <b>TEL 03-5665-1605</b>    <b>FAX 03-5665-1606</b> <b>*We would appreciate if you could e-mail us for any inquiries as the office is not attended at all times.</b></p>
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**Contact for inquiries on the release**

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