

日本の患者会の活動紹介

Activities of patient groups in Japan

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日本難病・疾病団体協議会(JPA)

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利害關係

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- Paid Instructor [no]
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日本の患者会の活動 1

Characteristics of patient groups in Japan 1

- 歴史的経過から 社会保障の拡充に関する活動が大きな柱であること
- 公害、薬害、医療被害に関する事件がきっかけになっている側面も大きいこと
- That, based on their history, activities relating to the expansion and strengthening of social security are their main pillar
- That the forming of the groups was largely prompted by incidents relating to pollution, drug-related diseases, and/or medical damages

日本の患者会の活動 2

Characteristics of patient groups in Japan 2

- 患者の人権に関する要素も大きいこと
- しかし、「難病」の原因究明と治療法の開発を求める活動が「難病」問題ではもっとも基本的な課題であること。
- That elements related to a patient's human rights are also a major factor
- That, as far as the issues of intractable diseases are concerned, the groups' most fundamental tasks and challenges are activities that call for the elucidation of the cause of such diseases and the development of a treatment method

日本の患者会の活動 3

Characteristics of patient groups in Japan 3

- 「難病」とは単に「希少疾患」や「難治性疾患」のことではなく、治療法がないことや原因が不明であること、そのことに基いて起きる社会的差別・偏見患者や家族の抱えている経済的な困難、介護負担や患者本人と家族を巻き込む精神的肉体的負担などの社会的側面を含む課題、と定義している。
- An intractable disease refers not only to a rare disease or a disease that is of refractory nature. Rather, it is defined as a disease having no treatment methods, and a disease whose cause is unknown, faced with challenges that encompass social aspects that arise from such a disease, such as (a) social discrimination and bias, (b) financial difficulties that the patient and his/her family must bear, (c) the burden of long-term nursing care, and (d) mental and physical burdens that involve the patient himself/herself and family members.

日本の患者会の活動 4

Characteristics of patient groups in Japan 4

- 日本の障害者福祉は、固定した身体の障害を対象としてきた歴史が長いことによって、疾病などによって引き起こされているさまざまな生活上の困難や社会や福祉の支援を必要とする患者を対象としないために、難病などの患者に対する福祉制度による支援は今日に至るまで正式な対象としてこなかった。そこから1972年に「難病患者」に対する特別な対策が始まった。
- Japanese welfare program for disabled patients has a long history of having targeted those with fixed physical disabilities. Because of this, it does not target patients who experience a variety of difficulties in daily living that are caused by a disease, or who require social and welfare assistance. Even today, assistance provided through welfare systems to patients with intractable and other diseases has not been regarded as an official program. This has paved the way to the launch in 1972 of a special measure targeting patients with intractable diseases.

日本の患者会の活動 5

Characteristics of patient groups in Japan 5

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2. 日本の患者会の「三つの役割」 1 Japanese patient groups have three roles to play. 1

1. 自分の病気を
正しく知ること

i) Getting to know
one's disease
accurately.

2. 患者・家族の
励ましあいと支えあい

ii) Promoting mutual
encouragement and
support between
patients and family
members

2. 日本の患者会の「三つの役割」 2 Japanese patient groups have three roles to play 2

3. 病気を持っていても
希望を持って生きて
いくことができる
社会作り

それはそれぞれに日本に
おける医療と福祉に起因
する背景と意味を持って
いる

iii) Creating a society where
patients can continue to live
with hope for the future,
despite their disease

Each of these roles has
backgrounds and
significances that stem from
Japan's medical treatment
and welfare.

3. JPAは日本における 最大の患者会連合組織(1)

The Japan Patients Association, or JPA, is the largest federation of patient groups in Japan. 1

構成は全国レベルの疾患患者会29団体、都道府県ごとの患者会連合会39団体で構成され、その組織人員はおよそ30万人となっている。

It is comprised of 29 national-level disease and patient groups, and 39 prefectural federations of patient groups. About 300,000 people belong to this organization as members.

3. JPAは日本における 最大の患者会連合組織(2)

The Japan Patients Association, or JPA, is the largest federation of patient groups in Japan. 2

ほかには小児難病親の会をまとめている「難病のこども支援全国ネットワーク」や連合会に所属していない「日本リウマチ友の会」などがある。

2010年にこの3団体が呼びかけて「難病・慢性疾患全国フォーラム」が開催された。

- Besides these, there are Nanbyo Net, or a nationwide network to support children with intractable diseases, that oversees groups of parents of children with intractable disease, and the Japan Rheumatism Friendship Association that does not belong to the JPA.
- In 2010, these three organizations jointly organized the Nationwide Forum for Intractable and Chronic Diseases.

3. JPAは日本における 最大の患者会連合組織(3)

The Japan Patients Association, or JPA, is the largest federation of patient groups in Japan. 3

このフォーラムには呼びかけ3団体の構成団体を含めて109団体が参加し、製薬企業や医療関係団体も名を連ねた。各政党の代表によるパネルディスカッションや日本学術会議議長の講演があり、患者会の体験発表も行われた。

This Forum was participated by a total of 109 organizations including the three component organizations that initiated the move. Pharmaceutical companies and medical-related organizations were also listed as participants. A panel discussion was held with representatives of various political parties taking part. There was also a lecture by the chairman of the Science Council of Japan, and presentations by patient association members who talked about their experiences.

3. JPAは日本における 最大の患者会連合組織(4)

The Japan Patients Association, or JPA, is the largest federation of patient groups in Japan. 4

- このフォーラムは2011年度も開催され、参加団体は123団体と増え、企業や関係団体の参加も増えた。ダウン症のこどもたちの感動的なダンスパフォーマンスが開幕を飾った。
- This Forum was held in 2011 as well, with the number of participating organizations increasing to 123. Participation by corporations and relevant organizations also increased. The program opened with a heartwarming and electrifying dance performance by Down's syndrome children.

3. JPAは日本における 最大の患者会連合組織(5)

The Japan Patients Association, or JPA, is the largest federation of patient groups in Japan. 5

- 厚生労働省より副大臣や局長、前大臣などが終始参加し、各政党の代表も壇上で挨拶をした。
- 国政における主な政党の中には「難病」に関する専門のワーキングチームを設置している党も少なくないこと。
- High-ranking officials from the Ministry of Health, Labour and Welfare consistently took part, including the Vice Minister, Bureau Directors and previous ministers, while representatives of various political parties appeared on the stage to address the audience.
- Quite a few major political parties in the national political scene of Japan are said to have set up an exclusive working team pertaining to intractable diseases.

4. 私達の願いと目的を実現するには In order to fulfill our wishes and goals

- グローバル化の進んだ現代社会においては1国内で完結できるものではなく、アジアの国々との交流を進めることは重要である。そして欧米先進諸国の患者会の活動に学ぶこと及び連携を強めることは非常に大切なことであると考えている。日本の患者会も国際社会においてその役割の一端を担うべきであると考えている。
- 本日はその実現のために日本の患者会活動の歴史において記念すべき第一歩となった。
- In our increasingly globalized contemporary society, fulfilling our wishes and goals cannot be done within a single country. It is important, therefore, to step up exchanges with other Asian countries. I also feel it extremely important to learn from the activities of other patient groups in the advanced nations of Europe and the US, and to strengthen our alliances. I believe that Japan's patient groups should play their roles in the international community.
- To make this possible, I think that today marks an important and memorable first step in the history of the activities of Japan's patient groups.

5. 最後に

In the end

- また、日本の患者会も国内外を問わず医療者・研究者との連携による、原因の究明・治療法の早期開発、創薬に関する研究協力を進めるべきであると考えている。
- もちろん今までも疾患ごとには患者会と研究者グループや製薬企業との連携と協力は進められてきたし、企業による患者会活動に対する支援や自治体による地域の患者会に対する支援も進められている。
- それらをどのように国にして進めるべきかという国家プロジェクト研究が始まり、JPAも積極的に関与する体制をとっている。
- I also feel that Japan's patient associations should collaborate with medical personnel and researchers, both in Japan and overseas, to elucidate the causes of intractable diseases, promptly develop the methods of treatment, and cooperate in researches pertaining to drug discovery and creation.
- Of course, patient groups have thus far been collaborating and cooperating with researcher groups and pharmaceutical companies, at least for individual diseases. Corporations have also been offering assistance to the activities of patient groups, while municipalities have been supporting various regional patient groups.
- A national project research has begun, focusing on how these activities ought to be carried out as a nation. The JPA is poised to become actively involved in the endeavor.