

# Diagnostic Consortium to Advance the Ecosystem for Hereditary Angioedema Annual Report for 2021

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  - \*Only Japanese

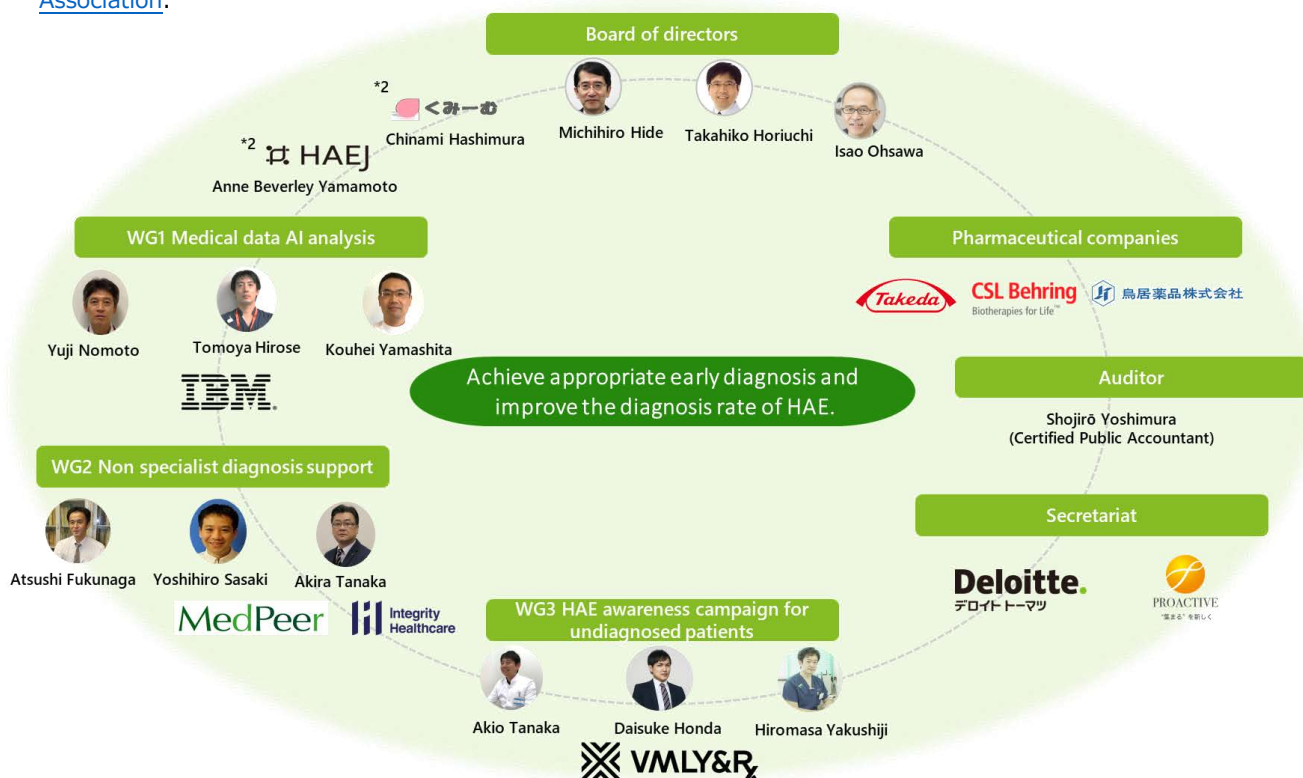
## « Main Story »

### 1. About us

#### ● Organization overview

Our association is working with a diverse range of stakeholders, including **physicians\*1**, **patient organizations**, **IT companies**, and **pharmaceutical companies**, in a **cross-industry** approach to early diagnosis and improvement of the diagnosis rate of HAE.

\*1 The photos represent physicians. For the affiliation of each doctor, please refer to the [Official Website of the Association](#).

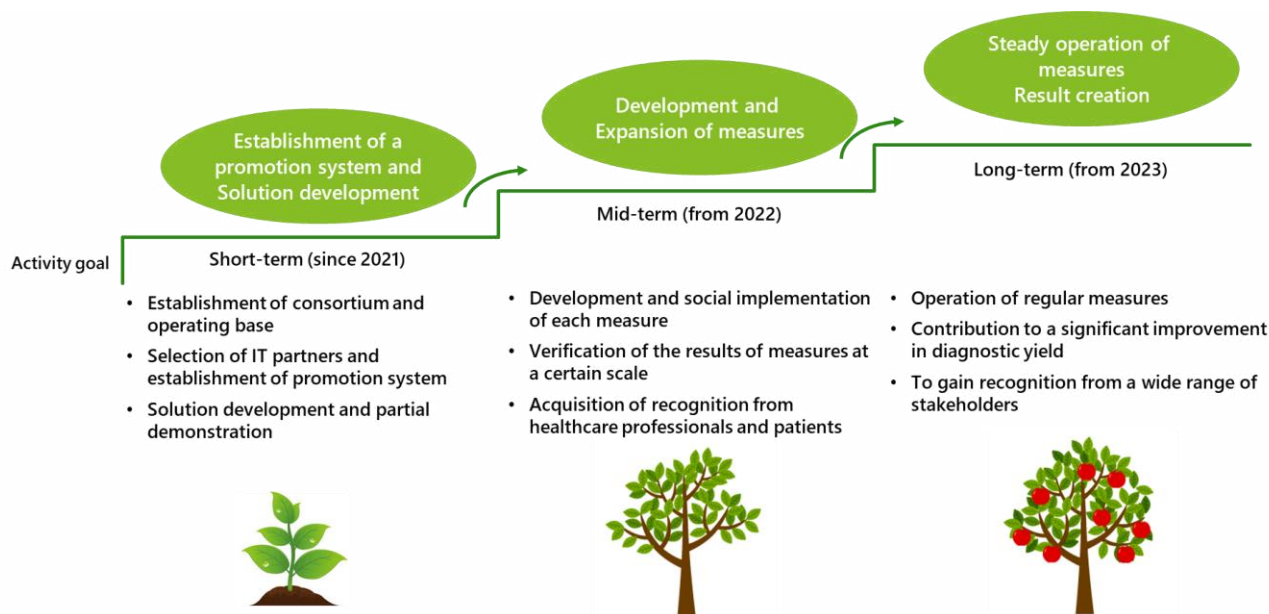


\*2 The HAEJ and くみーむ are both HAE patient associations.

## ● Goal

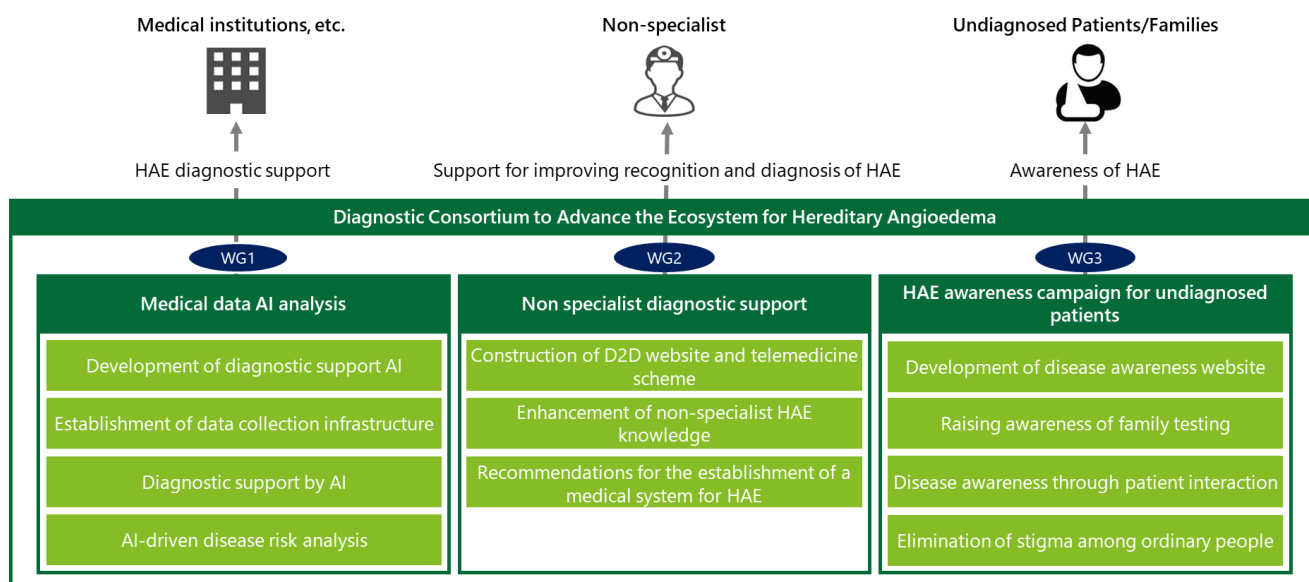
Our association is still under-recognized among the public and among healthcare professionals, and HAE diagnosis is less likely to be identified as a result.

Our goal is to achieve **early diagnosis and improvement of the rate of diagnosis of HAE** within five years. In the first year, we will build a promotion system and develop solutions. In the third year and beyond, we plan to expand the scale of measures and implement them regularly.



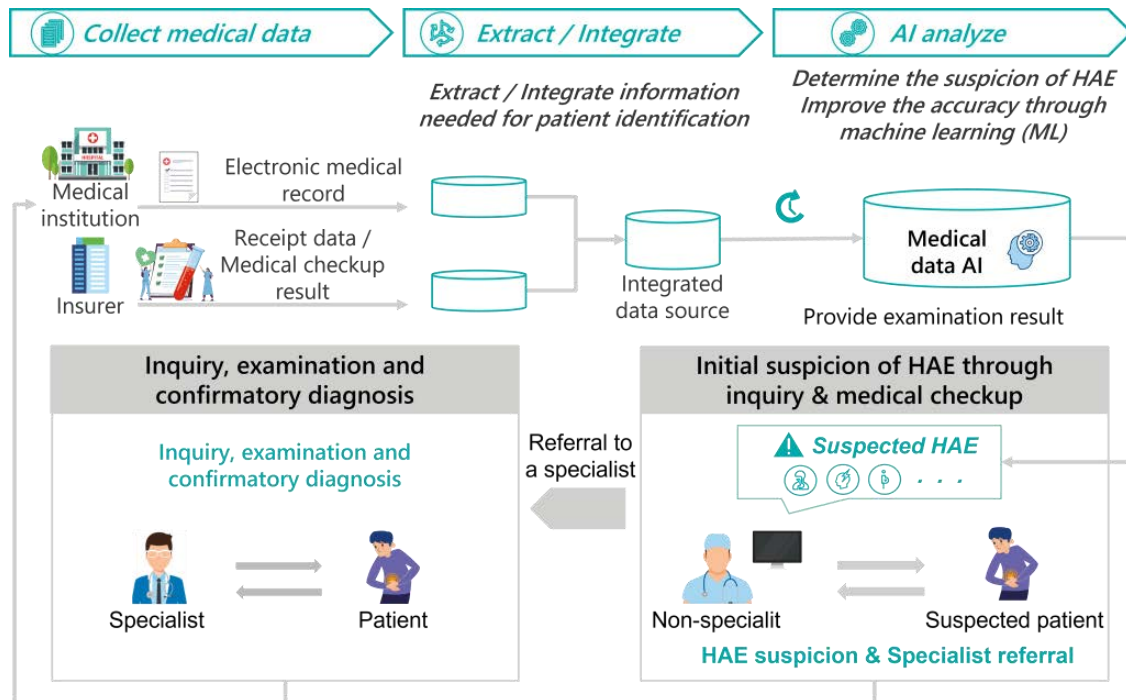
## ● Activities

Because HAE is a rare disease, it is often under-diagnosed due to low awareness of the disease by doctors and patients. Our association is working to **address issues through three working groups (WGs) to improve the early diagnosis and diagnostic yield of HAE.**



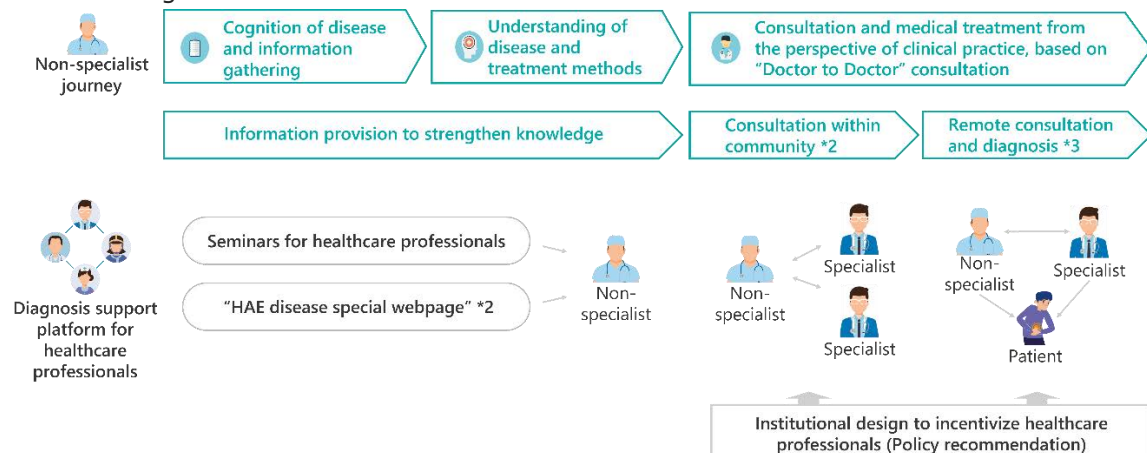
## « WG1 Medical Data AI Analysis »

In WG1, we will use medical big data to identify HAE patients based on electronic medical records and receipts, and provide **diagnosis support through artificial intelligence**. Using this AI, we aim to reduce the number of undiagnosed patients by reducing the omissions of "HAE" in daily medical care, and by building a system that detects suspected patients from big data such as receipt data and encourages them to visit specialized medical institutions.



## « WG2 Non-Specialist \* 1 Diagnostic Support »

As a diagnostic support activity for medical professionals including non-specialist doctors, WG2 opens a **special HAE webpage in the doctor web community**, which accounts for 40% of domestic doctors, and will hold several **seminars** at medical societies. In addition, we will promote early and appropriate diagnosis of doctors by utilizing a **remote consultation system** and building a mechanism that allows doctors to consult doctors who are familiar with HAE.



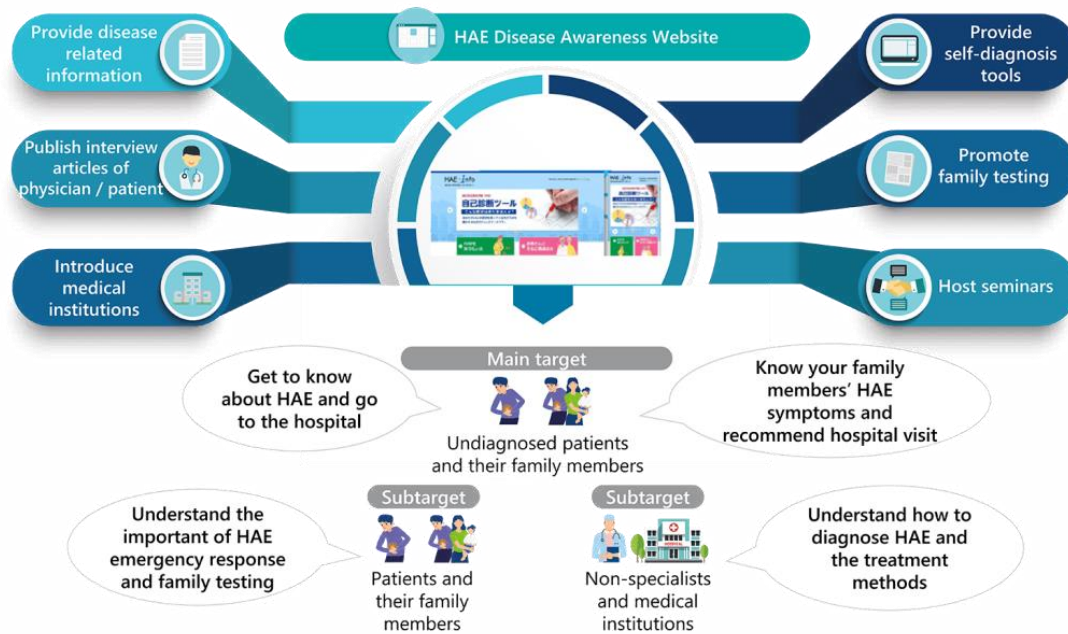
\*1: A doctor who is not certified by the Japan Council for the Evaluation and Certification of Medical Specialists, but has been dedicated to the treatment of HAE and patient support for many years

\*2: A special disease page will be set up in MedPeer to disseminate information and enable consultation using "Meet the Expert" in MedPeer, the existing web community.

\*3: Enable consultations using Integrity Healthcare YaDoc Quick

## « WG3 Disease Awareness Program for Undiagnosed Patients »

Through the **website**, WG3 provides information to help people recognize that they may have HAE, whilst also emphasizing the importance of testing the patient's family. By doing so, we aim for patients and their families to visit medical institutions with a greater peace of mind.

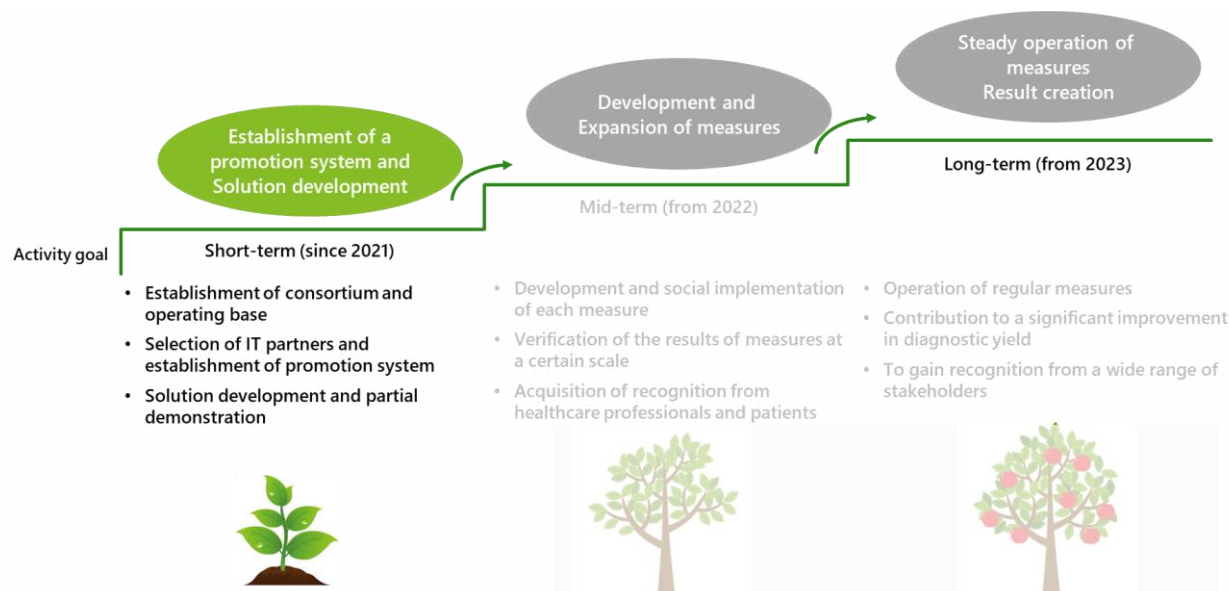




## 2. Achievements in 2021

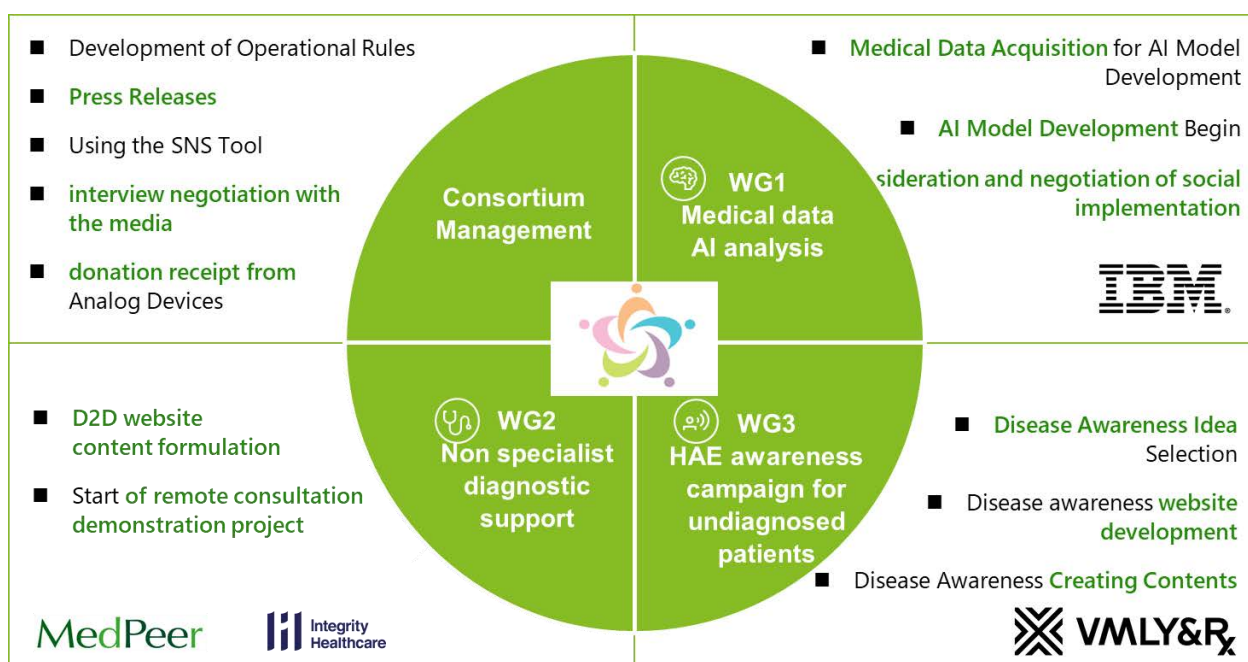
### ● Goal of the activities

In 2021, in addition to **establishing operating infrastructure and promotion system**, we also welcomed IT partners who provide digital solutions, and set the goal to **develop solutions and conduct partial demonstration tests** for development and social implementation in 2022 and beyond.



### ● Major achievements

**IBM Japan, Ltd., Integrity Healthcare Co., Ltd., Medpeer Co., Ltd., and VMLY&Rx**, which have extensive experience in the development and deployment of digital solutions in the medical industry, joined each WG to prepare and verify each measure, while corporate management focused on public relations activities.



## « Consortium Management »

- We have established basic rules to facilitate smooth operation of the consortium.
- We carried out **press releases** at the time of our establishment with participation of IT companies, which were introduced in up to 90 media outlets. In addition, an interview article between our representative director and Deloitte Tohmatsu Consulting GK, which serves as the secretariat, was published in **Harvard Business Review**, and an interview article of our representative director was published in **Pharmaceutical Affairs News**.

### Examples of media publications



- We opened **Twitter**, ([@discover0208](#)) and **Facebook** to raise awareness of HAE in society through information dissemination of our association activities. Please follow us.
- We are promoting **interviews with mass media** including key TV stations to improve recognition of HAE.
- We received a **donation** from **Analog Devices Inc.** for our efforts to contribute to ESG.



## « WG1 Medical Data AI Analysis »

- We **acquired US medical data** as the first data for the development of the initial AI model.
- Based on the medical field knowledge on HAE and the key points for diagnosis, we **started AI development** in cooperation with IBM Japan, Ltd.
- In order to implement AI society after 2022, we have started **cooperative negotiations of AI implementation** with medical institutions and companies with electronic medical record systems.

## « WG2 Non-specialist Diagnosis Support »

- In order to raise the awareness of HAE diseases among physicians, we conducted awareness activities in the platform MedPeer, **prepared a special disease page** for physicians, and started writing articles such as "Points for HAE diagnosis. ".
- In order to support the diagnosis of HAE by physicians, we have started a **demonstration test of a remote consultation service between physicians** in cooperation with the Society of Dental Medicine for the Diseased and related physicians. In recent years, the demand for remote consultation has been increasing due to the effects of infectious diseases, and we received an announcement that **19 doctors will participate** in the demonstration experiment. For remote consultation, we used the online medical care system "YaDoc Quick" of Integrity Healthcare Co., Ltd.
- Based on the interviews with the physicians concerned, we identified the medical departments where the need for HAE recognition was high and formulated a plan for **measures to improve disease recognition at relevant medical societies**.

### « WG3 Disease Awareness Program for Undiagnosed Patients »

- We listened to the issues and requests related to HAE disease awareness from the member NPO, HAEJ, the HAE patient association, and the pharmaceutical companies, and **examined the contents of the disease awareness website.**
- The WG Leaders, Dr. Anne Beverley Yamamoto, Director of our association (Representative of the NPO HAEJ), and VMLY&Rx. cooperated to start **creation of contents for disease awareness website.**

### Image of disease awareness website

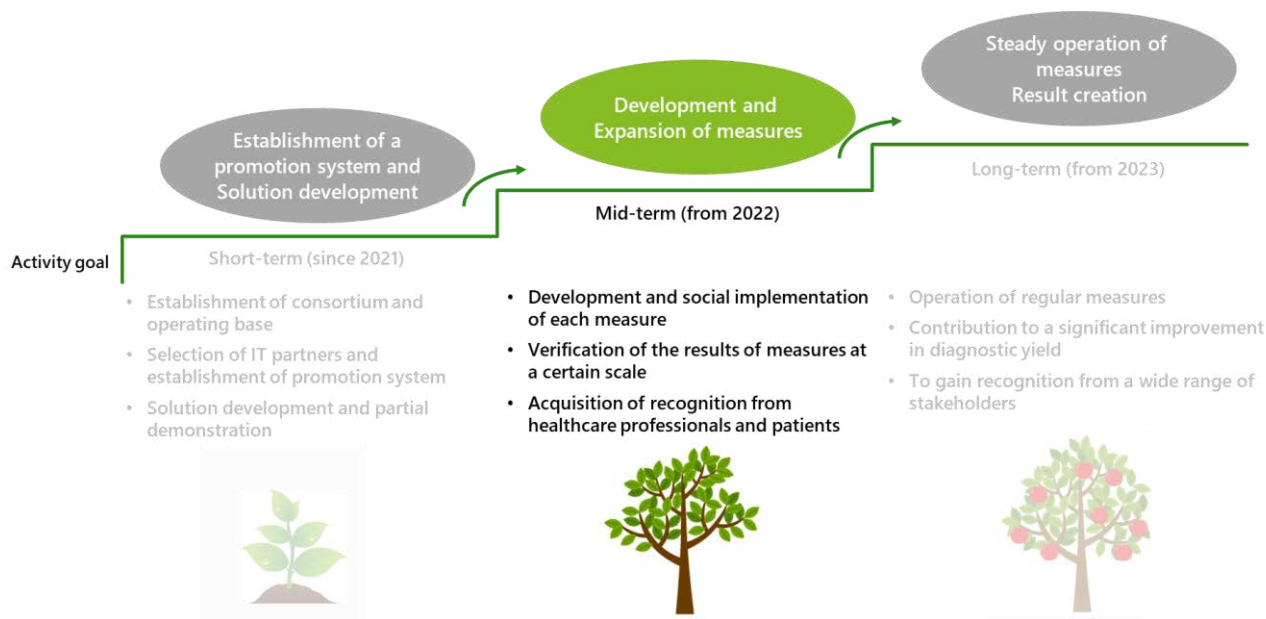




### 3. Activity goal for 2022

#### ● Goal

In 2022, we will devote ourselves to **corporate public relations** and promote **development and social implementation** of policies that we have already prepared. WG1 will work on **social implementation of AI**, WG2 will work on **publication of MedPeer disease special page, social implementation of remote consultation, and measures to raise awareness of HAE in medical societies**, and WG3 will work on **publication of the disease awareness website** to raise awareness of HAE among healthcare professionals and undiagnosed patients.



#### ● Key activities and roadmap

##### « Corporate Management »

- We will promote **interview with mass media and program production companies**, including key TV stations, to raise awareness of HAE diseases.
- In the lead up to **HAE Day** in May, we plan to implement disease awareness measures using SNS and the web\*.

##### « WG1 Medical Data AI Analysis »

- In cooperation with the WG Leader physician and IBM Japan, we will analyze the aforementioned US medical data and **promote AI development** by October (planned).
- In parallel with AI development, for social implementation, we will proceed with **negotiations towards AI implementation** with medical institutions, companies with electronic medical record systems, and health insurance societies.

##### « WG2 Non-specialist Diagnosis Support »

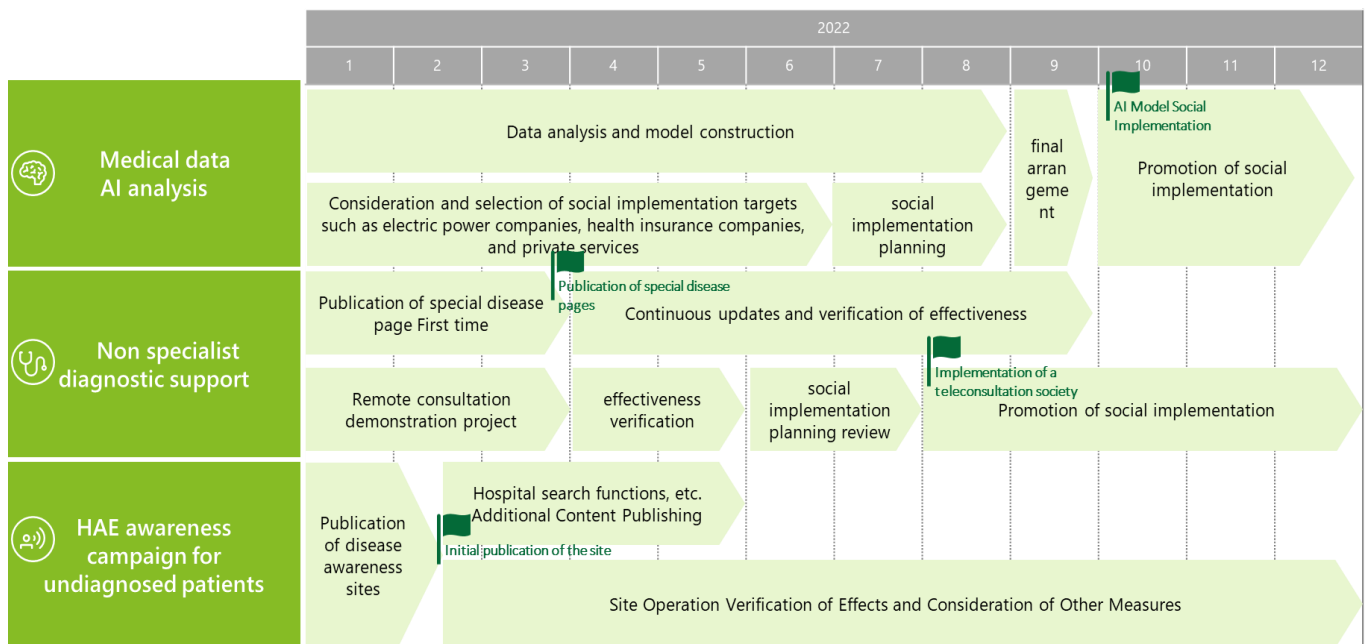
- A **Disease Special Page in MedPeer** will be launched (planned for March). In the first article, the WG Lead Physician explains the diagnostic points of HAE which can be easily misdiagnosed.

- We will verify the effectiveness of the remote consultation demonstration project and improve the operation and system aspects. After that, we will **promote social implementation** (scheduled for August).
- The aim is to raise awareness of the disease through publicity activities such as **seminars and poster displays at medical societies for internal medicine and dentistry**.

« **WG3 Disease Awareness Program for Undiagnosed Patients** »

- We will launch a **disease awareness website** (scheduled for March). In the initial content, the disease outline of HAE, precautions in daily life, medical expense subsidy system, etc. are introduced.
- After the launch of the website, we will consider **measures to raise awareness of diseases other than through the web** in order to increase the recognition rate of HAE in general society through various approaches. We will conduct interviews with a wide range of stakeholders, including WG leaders, physicians, the NPO HAEJ, the HAE patient association, and pharmaceutical companies, and reflect their diverse perspectives.

## 2022 Roadmap



#### 4. Financial condition (only Japanese)

## 2021 年度決算報告書

自 2021 年 2 月 8 日

至 2021 年 12 月 31 日

一般社団法人 遺伝性血管性浮腫診断コンソーシアム

## 貸借対照表

2021年 12月31日現在

一般社団法人 遺伝性血管性浮腫診断コンソーシアム

(単位:円)

科 目	当年度	前年度	増 減
I 資産の部			
1. 流動資産			
現金預金	415,032,149	0	415,032,149
流動資産合計	415,032,149	0	415,032,149
2. 固定資産			
ソフトウェア	3,709,499	0	3,709,499
固定資産合計	3,709,499	0	3,709,499
資産合計	418,741,648	0	418,741,648
II 負債の部			
1. 流動負債			
未払金	42,389,388	0	42,389,388
未払法人税等	58,200	0	58,200
流動負債合計	42,447,588	0	42,447,588
負債合計	42,447,588	0	42,447,588
III 正味財産の部			
1. 基金	400,000,000	0	400,000,000
2. 一般正味財産	△ 23,705,940	0	△ 23,705,940
正味財産の部合計	376,294,060	0	376,294,060
負債及び正味財産合計	418,741,648	0	418,741,648

## 正味財産増減計算書

2021年 2月 8日から2021年 12月31日まで

一般社団法人 遺伝性血管性浮腫診断コンソーシアム

(単位:円)

科 目	当年度	前年度	増 減
<b>I 一般正味財産増減の部</b>			
1. 経常増減の部			
(1) 経常収益			
受取寄付金	81,000,000	0	81,000,000
受取寄付金	81,000,000	0	81,000,000
雑収益	3,375	0	3,375
受取利息	3,375	0	3,375
経常収益計	81,003,375	0	81,003,375
(2) 経常費用			0
事業費	43,070,644	0	43,070,644
委託費	42,946,200	0	42,946,200
通信運搬費	6,458	0	6,458
ソフトウェア減価償却費	49,546	0	49,546
広告宣伝費	67,650	0	67,650
雑費	790	0	790
管理費	61,580,471	0	61,580,471
通信運搬費	7,893	0	7,893
ソフトウェア減価償却費	111,665	0	111,665
消耗品費	30,580	0	30,580
租税公課	113,313	0	113,313
業務委託費	60,588,000	0	60,588,000
広告宣伝費	726,000	0	726,000
雑費	3,020	0	3,020
経常費用計	104,651,115	0	104,651,115
評価損益等調整前当期経常増減額	△ 23,647,740	0	△ 23,647,740
評価損益等計	0	0	0
当期経常増減額	△ 23,647,740	0	△ 23,647,740
2. 経常外増減の部			0
(1) 経常外収益			0
経常外収益計	0	0	0
(2) 経常外費用			0
経常外費用計	0	0	0
当期経常外増減額	0	0	0
税引前当期一般正味財産増減額	△ 23,647,740	0	△ 23,647,740
法人税、住民税及び事業税	58,200	0	58,200
当期一般正味財産増減額	△ 23,705,940	0	△ 23,705,940
一般正味財産期首残高	0	0	0
一般正味財産期末残高	△ 23,705,940	0	△ 23,705,940
<b>II 指定正味財産増減の部</b>			
当期基金増減額	400,000,000		
基金期首残高	0		
基金期末残高	400,000,000		
<b>III 正味財産期末残高</b>	376,294,060		



## 正味財産増減計算書内訳表

2021年 2月 8日から2021年 12月31日まで

一般社団法人 遺伝性血管性浮腫診断コンソーシアム

(単位: 円)

科 目	公益目的事業会計				法人会計	合計
	WG 1	WG 2	WG 3	小計		
I 一般正味財産増減の部						
1. 経常増減の部						
(1) 経常収益						
受取寄付金	0	0	0	0	81,000,000	81,000,000
受取寄付金					81,000,000	81,000,000
雑収益	0	0	0	0	3,375	3,375
受取利息					3,375	3,375
経常収益計	0	0	0	0	81,003,375	81,003,375
(2) 経常費用						0
事業費	38,720,500	4,300,598	49,546	43,070,644	0	43,070,644
委託費	38,720,000	4,226,200		42,946,200		42,946,200
通信運搬費		6,458		6,458		6,458
ソフトウェア減価償却費			49,546	49,546		49,546
広告宣伝費		67,650		67,650		67,650
雑費	300	290		790		790
管理費	0	0	0	0	61,580,471	61,580,471
通信運搬費					7,893	7,893
ソフトウェア減価償却費					111,665	111,665
消耗品費					30,580	30,580
租税公課					113,313	113,313
業務委託費					60,588,000	60,588,000
広告宣伝費					726,000	726,000
雑費					3,020	3,020
経常費用計	38,720,500	4,300,598	49,546	43,070,644	61,580,471	104,651,115
評価損益等調整前当期経常増減額	△ 38,720,500	△ 4,300,598	△ 49,546	△ 43,070,644	19,422,904	△ 23,647,740
評価損益等計	0	0	0	0	0	0
当期経常増減額	△ 38,720,500	△ 4,300,598	△ 49,546	△ 43,070,644	19,422,904	△ 23,647,740
2. 経常外増減の部						
(1) 経常外収益						
経常外収益計	0	0	0	0	0	0
(2) 経常外費用						
経常外費用計	0	0	0	0	0	0
当期経常外増減額	0	0	0	0	0	0
税引前当期一般正味財産増減額	△ 38,720,500	△ 4,300,598	△ 49,546	△ 43,070,644	19,422,904	△ 23,647,740
法人税、住民税及び事業税	0	0	0	0	58,200	58,200
当期一般正味財産増減額	△ 38,720,500	△ 4,300,598	△ 49,546	△ 43,070,644	19,364,704	△ 23,705,940
一般正味財産期首残高	0	0	0	0	0	0
一般正味財産期末残高	△ 38,720,500	△ 4,300,598	△ 49,546	△ 43,070,644	19,364,704	△ 23,705,940
II 指定正味財産増減の部						
当期基金増減額				0	400,000,000	400,000,000
基金期首残高	0	0	0	0	0	0
基金期末残高	0	0	0	0	400,000,000	400,000,000
III 正味財産期末残高	△ 38,720,500	△ 4,300,598	△ 49,546	△ 43,070,644	419,364,704	376,294,060



一般社団法人 遺伝性血管性浮腫診断コンソーシアム

## 附属明細書

1. 基本財産及び特定資産の明細  
記載すべき事項はありません。
2. 引当金の明細  
記載すべき事項はありません。

以 上

## 財務諸表に対する注記

2021年 2月 8日から  
 2021年12月31日まで

### 1. 重要な会計方針に係る事項に関する注記

#### 1. 固定資産の減価償却方法

- (1) 無形固定資産  
法人税法の規定に基づく定額法を採用しております。

#### 2. 消費税等の会計処理

消費税等の会計処理は税込方式を採用しております。

#### 3. 固定資産の取得価額、減価償却累計額及び当期末残高

固定資産の取得価額、減価償却累計額及び当期末残高は、次のとおりです。

(単位：円)

科 目	取得価額	減価償却累計額	当期末残高
ソフトウェア	3,870,710	161,211	3,709,499
合 計	3,870,710	161,211	3,709,499

以 上

## 監査報告書

2022年2月9日

一般社団法人 遺伝性血管性浮腫診断コンソーシアム

代表理事 秀 道広 殿

代表理事 堀内孝彦 殿

一般社団法人 遺伝性血管性浮腫診断コンソーシアム

監事 吉村祥二郎



私監事は、2021年2月8日から2021年12月31日までの事業年度の理事の職務執行の監査を行いました。これにより、一般社団法人及び一般法人に関する法律第99条第1項（同法第197条において準用する第99条1項）に基づき監査報告書を作成しましたので、以下の通り報告いたします。

### 1. 監査の方法及びその内容

私監事は、理事及び使用人等と意思疎通を図り、情報の収集及び監査の環境の整備に努めるとともに、理事会その他重要な会議に出席し、理事及び使用人等からその職務の執行状況について報告を受け、必要に応じて説明を求め、重要な決裁書類等を閲覧し、主要な事業所において業務及び財産の状況を調査いたしました。以上の方法に基づき、当該事業年度に係る事業報告について検討いたしました。

さらに、会計帳簿又はこれに関する資料の調査を行い、当該事業年度に係る財務諸表等（貸借対照表、正味財産増減計算書（正味財産増減計算書内訳表を含む）、財産目録、財務諸表に対する注記）及びその附属明細書について検討いたしました。

### 2. 監査の結果

#### (1) 事業報告等の監査結果

- 一 事業報告は、法令及び定款に従い、法人の状況を正しく示しているものと認めます。
- 二 理事の職務の執行に関する不正の行為又は法令もしくは定款に違反する重大な事実は認められません。

#### (2) 財務諸表等及びその附属明細書の監査結果

財務諸表等及びその附属明細書は、法人の財産及び損益の状況をすべての重要な点において適正に表示しているものと認めます。

以上