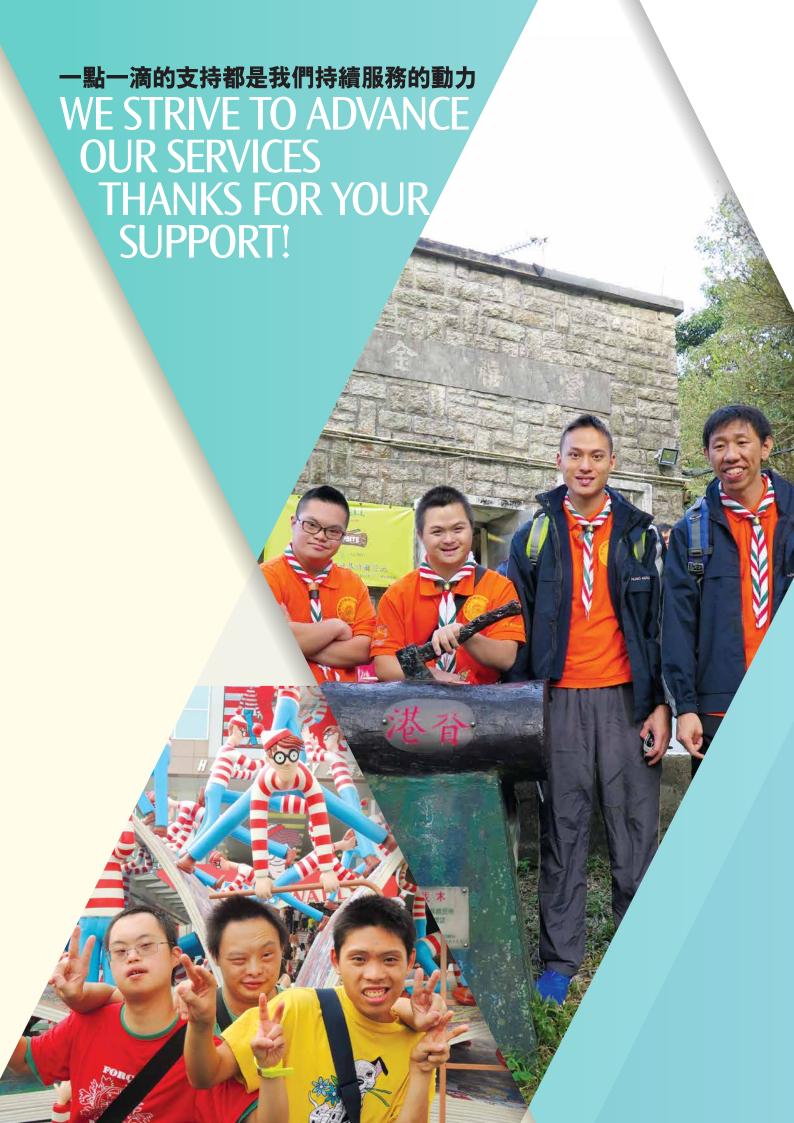




## 我們·連繫在一起 WE LINK TOGETHER

縱橫的線條象徵著香港唐氏綜合症協會各成員與我們的社會緊緊相連,互相扶持,互相影響,互相連繫,無限伸延......

These vertical and horizontal lines symbolize the endless interwoven relationship among members, associates of the Hong Kong Down Syndrome Association and our society characterised by positive interaction, mutual support and influence. Linking Together and Ever ...





## 協會簡介 INTRODUCTION OF HKDSA

#### 簡介 Introduction

香港唐氏綜合症協會於一九八七年十月正式註冊為非牟利慈善團體,致力為唐氏綜合症人士、殘疾人士、其他智障人士及其家人提供綜合家庭支援及職業復康服務,使服務使用者在個人成長及生活各方面,得以全面發展;以及滿足他們在就業及職業培訓方面的需要。

Registered as a non-profit-making organization in October 1987, the Hong Kong Down Syndrome Association is committed to serving individuals with Down Syndrome, the disabled, people with intellectual disabilities and their family members with integrated family support and vocational rehabilitation services. Our objective is to enable the service users to develop their personal growth fully and in every aspect of life, as well as to meet their employment and vocational training needs.



#### 信念 Belief

殘疾人士在社會的支持下,應享有充分的機會去發揮個人的潛能,及積極參與他們在生活上的各項決定,以確保其在社會上的平等機會。

People with disabilities should be given opportunities to unlock their full potential and take part in the decision-making of every aspect of their lives, so as to enjoy equal rights and opportunities in a supportive environment.

#### 宗旨 Mission

改善唐氏綜合症人士及其他殘疾人士及其家人的生活質素。

To improve the quality of life of persons with Down Syndrome or other disabilities, as well as their families.

#### 何謂唐氏綜合症 What is Down Syndrome?

一般人在每個細胞中有四十六條染色體,而唐氏綜合症人士的細胞則通常有四十七條。這一條額外的染色體,為他們帶來外貌上和智力上的特徵。他們只要及早接受適當的訓練及支援,唐氏綜合症的人士也可以過著愉快和獨立的生活。

There are 46 chromosomes in each cell of a person. However, in the cells of a person with Down Syndrome, there are 47. This extra chromosome is the cause of distinct physical appearance and intellectual status of people with Down Syndrome. If appropriate training and support could be given at early stages, people with Down Syndrome may be able to live happily and independently.

#### 目標 Objectives

- 改善大眾對唐氏綜合症人士的觀感。
   To improve the public perception of individuals with Down Syndrome.
- 代表唐氏綜合症人士及其家人向大眾作推廣及介紹。
   To promote and introduce the Association's messages to the public on behalf of individuals with Down Syndrome, as well as their family members.
- 辨識唐氏綜合症人士、其他殘疾人士及其家人的需要,並尋求滿足此需要的途徑。
   To identify the needs of individuals with Down Syndrome and other disabilities as well as their family members, and seek ways to satisfy such needs.
- 給予唐氏綜合症人士、其他殘疾人士資訊及充分支持,以確認家長們是兒童的主要倡導者。
  To provide information and full support to individuals with Down Syndrome and other disabilities, and recognize parents as the key guardians of their children.
- 營造一種協調的氣氛, 使唐氏綜合症人士、其他殘疾人士、其家人及專業人士能在彼此尊重下, 建立充滿動力的伙 伴關係。

To create an amiable atmosphere so that individuals with Down Syndrome and other disabilities, as well as their family members, and professionals can forge a dynamic partnership in a respectable environment.

向有關機構及政府部門作出評論、建議,並提供資料,藉以改善給予唐氏綜合症人士、其他殘疾人士及其 家人的服務。

To submit comments and suggestions and provide information to the relevant authorities and government bodies so as to improve services for people with Down Syndrome and other disabilities, as well as their family members.



#### 丰庸的詩

## CHAIRMAN'S MESSAGE

多年以來,香港唐氏綜合症協會堅守信念,認為智障和殘疾人士應享有充份的機會發揮個人潛能。協會更以持續改善會員、服務使用者及其家人的的福祉和生活質素為目標,積極配合他們在生活上的各項安排,並爭取其在社會上獲得平等對待和機會。

本人參加協會多年,榮幸於2015年獲選為主席。大家對我的信任和厚愛,本人深表謝意。我理解會員和幹事們對協會主席的期望,令我更感任重道遠,肩負使命。本人將與會長、副會長及專業顧問、各委員會、員工、家長、會員/服務使用者和義工們一起努力,達致發展協會、服務會員受衆的共同目標。

Over the years, the Hong Kong Down Syndrome Association maintains that people with disabilities should be given ample opportunity to develop their potentials. The Association is committed to improving the wellbeing and quality of life of members, service users and their families, and becoming a partner at every stage of their lives, with a view to protecting their rights in the society.

I have been with the Association for several years. It was my honor to be elected as Chairman of the Executive Committee in the Annual General Meeting 2015. I am grateful for your confidence and trust, and I am humbled by the expectations of our members on me as the Chairman. It is a very tall order, and I will continue to work with the President, Vice Presidents, professional advisors, committee members, office staff, parents, members/service users and volunteers to further improve the wellbeing of Down's and other people with disabilities, as well as their families.



#### 同心協力 緊密連繫 Unity & Intimacy

協會過去30年的發展和成果得來不易,實有賴贊助本會的各個社會團體、慈善基金、政府機構的支持,家長、會員/服務使用者的信任和參與,各委員會成員的指導,以及全體同工及義工的努力,香港唐氏綜合症協會的團隊能量才能得以發揮。我謹代表協會向各位致以衷心謝意,更感謝會長鄧永鏘爵士、兩位副會長阮偉文博士和劉嘉玲小姐的信任,期盼我們繼續努力,擴展協會聯繫網絡,共同建立一個關愛與共融的社區。

The progress and achievement of the Association over the past 30 years have been well recognized. It stems from the support of our partner organizations, charitable foundations and government agencies. The collective wisdom and energy of parents, members/service users, committee members, as well as staff members and volunteers, have made our Association like a family with love and care for all. On behalf of the Association, I would like to express my heartfelt gratitude to President of the Association, Sir David Tang, Vice Presidents Dr Andrew Yuen and Miss Carina Lau, for their unfailing support. We shall continue the team work and expend our network of partners, sponsors and supporters, for the benefits of our members and the community of people with disabilities as a whole.



#### 伙伴合作 關愛共融

2015/2016是一個充滿機遇的年度。喜見協會在幫助會員/服務使用者全人發展、擴展外界不同團體伙伴關係的工作上不遺餘力,取得豐碩的成果。協會一直獲得不少友好機構及團體支持及贊助,合作舉辦多姿多彩的共融及籌款活動,包括愉景灣第12屆慈善網球賽、香港女子俱樂部的游泳馬拉松、九龍金域扶輪社周年聖誕派對、的近律師行的聖誕童騎樂、荷花集團的贊助等,活動為會員/服務使用者帶來不少新的體驗,所獲的善款及贊助亦促進了協會的服務發展。

協會更於年初舉行全港賣旗日,是次活動共招募了近1700名義工,籌得善款約港幣106萬元。能有此佳績,實有賴各學校、團體、家長、會員/服務使用及義工的鼎力支持。今年賣旗日適逢農曆新年期間,我們喜獲本會副會長劉嘉玲小姐擔任祝福大使,非常感謝。

2015/2016 was a year filled with opportunities. The Association has spent tremendous effort on the whole person development of members/service users, as well as on initiatives and active engagements with community groups, with remarkable successes. At the same time, we have continued to build and strengthen our partnerships with many institutions and groups to co-organize community inclusion and caring programmes. Among them are Discovery Bay 12th Charity Tennis Cup, Hong Kong Women's Club Swimathon, the annual Christmas Party of Rotary Golden Mile, Ducan and Ride for Disabled and the Eugene Group sponsorship, etc. The events not only brought a lot of valuable experiences to the members/service users, but the donations and sponsorships also helped to spur the Association's service development.

The Association also held a territory-wide Flag Day on February 13, 2016, around the time of Chinese New Year. A total of 1,700 volunteers were recruited and HK\$1.06 million raised. The success was attributable to the support of participating schools, organizations, parents, members/service users and volunteers. We were also very fortunate and grateful to have our Vice President, Miss Carina Lau, as our Goodwill Ambassador.

協會一直關心會員和家長的需要,除透過家長委員會及服務委員會收集意見外,亦多次舉辦獨立調查研究,以不斷優化服務。數月前我們發佈了《唐氏綜合症會員需要及家屬身心健康指數》調查,結果反映了會員對的健康關注和殷切的醫療服務需要,以及家長對子女成長的憂慮和所面對的壓力。因應調查結果,我們向政府相關部門提出了多方面的服務建議。另外,協會因應會員/服務使用者老齡化的情况,正進行一項調查,探討現行服務的不足,我們期盼早日與大家一起分享調查結果,積極和用心回應服務需要。

The Association has been concerned with the wellbeing of members and parents. In addition to consulting the Parents Committee and Service Committee, research surveys are also conducted to understand the needs and wants of our service receivers. Between 2015/2016, we published the survey result of 'Needs of DS People and Mental Health Condition of Caregivers ', which reflects the health challenges of people with Down and other intellectual disabilities, their demands for medical care and worries about their children's growth, as well as the pressures they endure in daily life. Based on the findings, we have made recommendations to relevant government departments, and are following up as necessary. Moreover, in view of the growing population of aging members/ service users, we conducted another survey to expose the areas of inadequacy in existing services. We look forward to sharing the findings and taking actions accordingly.

協會去年收入約為二仟三佰五拾六萬,比前年上升近12%,當中三佰四拾萬是籌款和捐助的收入,比上年上升了87%。協會現時的營運開支約6成由社會福利署津助,其餘4成由協會自行籌款和申請外間贊助。我們將持續開拓資源,整固發展。一方面支持自付盈虧的服務,另一方面優化和推展新計劃,以滿足服務需求,盡最大努力持續而有效地改善會員/服務使用者的生活質素,並讓更多的唐氏綜合症及智障人仕得到協會的幫助。

Last year, the Association's revenue was about \$23.56million, up 11.8% from the year before. Of this amount, \$3.4 million was from fundraising and donation, up 87% from the previous year. About 60% of the Association's operating expenses is subsidized by the Social Welfare Department, with the balance raised by the Association itself. We will continue our relentless effort to garner resources and spur developments, so as to sustain our self-financed services and create new ones to meet the changing needs of our members and their families.

### 總幹事報告 DIRECTOR'S REPORT

回顧過去一年,協會發展穩健,一方面繼續改善服務,推動多元化體藝活動和關顧會員/服務使用者身心社靈全人發展;另一方面,與委員會和職員們製定協會三年策略計劃,確定發展方向和加強團隊精神。主要工作包括:

Looking back over the past year, the Association has been developing steadily. On the one hand, we continued to improve services, promote diversified art/sports activities and care for the comprehensive needs of the members/service users. On the other hand, we formulated a three-year strategic plan with the Committees and staff team. We set and determined the direction of development and strengthened the team spirit. The main work includes:



社會發展迅速,對社會服務的期望和要求上升, 機構管理要有透明度和清晰交待。回應這些轉變,協會去年由製定年度計劃改為三年計劃,定立 明確發展目標方向,預算所需要的資源和人才管理。 去年,為管理層員工舉行了「三年策略計劃」培訓工作坊, 還有兩場「員工大會」,旨在與員工溝通和收集意見, 共同製定協會未來發展方向。

Society develops rapidly. There are increased expectations and demands for social services, transparency and accountability in welfare organisation. In response to these changes, the Association last year changed from the development of the annual plan to three-year plan. We set clear goals and direction of the development. We planned and forecasted the resources needed including talent development. Last year, three-year strategic plan training workshops were held for management staff and two "staff conventions" were held in order to communicate with staff and collect views on the strategic plan.



To enhance the quality of service and to monitor the effectiveness, the Association set up a Working Group on Service Quality Standard. We conducted internal inspections on a regular basis and proposed improvement plan. Last year, the Association revised and updated the Policy Paper on "SQS 5" and reviewed the relevant documents and implementation of the SWD subvented service units. In addition, we set the indicators of the implementation of efficiency management for the services. To assess the service effectiveness, a management research was conducted on the services provided to members / service users in the face of aging. The research was led by Professor Terry LUM from the University of Hong Kong. It aimed to assess the effectiveness of existing services if adequately addressed the aging needs of service users and to make recommendations. Moreover, with regard to aging, the Association continued the project sponsored by the Chow Tai Fook Charity Foundation namely Industious Adulthood and Positive Ageing for People

with Down Syndrome or Intellectual Disabilities. We

research for the project.

delivered a series of programs to encourage

service users to establish healthy lifestyle and to

meet the challenges of ageing. The Association

appointed Ms Donna WONG, Honorable Researcher of the University of Hong Kong

Sau Po Center to conduct the evaluation

提升服務質素,檢視成效 To enhance the quality of service and **↑** to monitor the effectiveness

協會成立服務質素監察工作小組,定期進行內部檢視,提出改善方案。去年,協會修改和更新了《服務質素五》的政策文件,並重新檢視受社署津助服務單位相關文件和執行情況。除此,推行積效管理,為服務輸出和標準制定指標。眼見會員/服務使用者面對老齡化情況,協會進行一項服務調查,探討現有服務能否有效照顧服務使用者老齡化的需要和提出建議方案,這項調查協會委托了香港大學林一星教授進行。另外,在關注老齡化方面,協會繼續獲「周大福慈善基金」贊助,推行唐氏綜合症/智障人士一「勤懇樂業在盛年●健康積極享晚年」計劃,提倡透過有趣方式鼓勵服務使用者建立健康生活模式,迎接晚年挑戰,協會更委托香港大學秀圃老年研究中心榮譽研究員楊黃錦賓女士進行計劃成效研究調查。



#### 拓展資源<sup>,</sup>建立品牌 Expand resources, build brand

協會積極建立伙伴,舉行不同類型的合作計劃和活動,更主動申請外界贊助和基金。去年,協會成功申請到公益金撥款\$1,331,775贊助《甜心學堂》2016至2019年的計劃經費,以提供及早介入的專業訓練給0至6歲的唐氏綜合症的兒童。協會繼續善用不同媒介宣傳服務,推廣共融關愛,除安排和接受不同媒體訪問,設計新協會網頁和面書專頁,並定期更新內容,讓大眾能更快得到協會的資訊。協會亦榮獲政府資訊科技局撥款\$380,000贊助開發《至Fit至叻唐寶寶》手機應用程式,藉此平台推出特別針對唐寶寶的大小肌肉遊戲,更有唐寶寶故事,手機程式預計於2017年初推出。除此,協會制定會徽和宣傳品印刷指引,以優化和統一宣傳品的標準。

The Association actively builds partnerships, holds various types of cooperation programs and activities, and takes the initiative to apply for outside sponsorship and funds. Last year, the Association successfully applied for the Community Chest Grant \$ 1,331,775 to sponsor the "SweetieLand" project for 2016-2019. The project aimed to provide early intervention and professional training for Down Syndrome children aged 0 to 6 years. In addition to arranging and receiving different media interviews, the Association has continued to make use of different media publicity. We completed website revamping and launched Facebook pages. We regularly updated its contents so that the public can get more information from the Association. The Association has also received a \$ 380,000 grant from the Government for the development of the "Fit and Smart DS Kids" mobile apps, which will feature fine motor and gross motor games specially designed

for Down Syndrome Children. The program is

emblems and publicity materials.

expected to be launched in early 2017. In addition,

the Association has developed guidelines of

corporate identity so as to standardize printing

#### 無言感激 Speechless gratitude

最後,我衷心感謝委員會的支持,員工們的努力,感謝他們盡心盡力的奉獻,以及 社會各界對本會服務的支持,讓我們能夠 為會員/服務使用者提供適切的服務,共同 建設和諧及關愛的社會。

Finally, I would like to thank the Committees for the support, the efforts made by the staff. Deeply appreciate their dedication and effort for our services, contributing to provide appropriate services to our members / service users to build a harmonious and caring society.

#### 楊冰梅 Ms. Maggie P. M. Yeung

總幹事 Director



## 組織架構 ORGANIZATION STRUCTURE

會長 President

副會長 Vice-Presidents

#### 執行委員會 Executive Committee

財務委員會 Finance Committee

人力資源委員會 Human Resources Committee

服務委員會 Services Committee

家長委員會 Parent's Committee

#### 總幹事 Director

#### 中央行政 Central Administrative

#### 綜合家庭支援服務 Integrated Family Support Services

白普理家長資源中心 Bradbury Parents Resource Centre

唐家軒 DS Centre

初生唐氏嬰兒家長支援服務 — 「甜心學堂」

Support Service for new born & preschool children with Down Syndrome - SweetieLand

網「樂」共享 The SHARE Project

「勤懇樂業在盛年 健康生活享晚年」計劃 IP Project

#### 綜合職業復康服務 Integrated Vocational Rehabilitation Services

卓業中心

Tiptop Training Centre

就業輔導中心

Employment Services Centre

社會企業 — 唐氏群毅服務隊 Social Enterprise – Down's Kwan Ngai Service Team



### 執行委員會、小組委員會及工作小組名單

## MEMBERS OF EXECUTIVE COMMITTEE, SUB-COMMITTEE AND WORKING GROUP

陳伯齡先生	Mr. Jonathan Chamberlain	創辦人	Founder
梁唐青儀女士	Mrs. Regina Leung	贊助人	Patron
鄧永鏘先生, KBE	Sir. David Tang, KBE	會長	President
阮偉文先生	Dr. Andrew Yuen	副會長、	Vice-president,
1701477702	2.17 (1.9.101)	籌募顧問	Fundraising Advisor
劉嘉玲女士	Ms. Carina Lau Ka Ling	副會長	Vice-president
陳肖齡女士, BBS	Ms. Ophelia Chan, BBS		
楊黃錦賓博士	Dr. Donna Wong		
盧鎮榮先生	Mr. C.W. Lo	專業顧問	Professional Advisor
麥家信先生	Mr. Andy K.S.Mak	-1->/C/EX(-1	Troicssional Advisor
梁達強先生	Mr.Liang Tat Keung, Kenneth		
史泰祖醫生, JP	Dr. Shih Tai Cho, Louis, JP		
余則文醫生	Dr. Yu Chak Man, Aaron	醫學顧問	Medical Advisor
郭偉明醫生	Dr. Henry Kwok		Wiedled / Avisor
陸乃明醫生	Dr. Luk Nai Ming		
李瑜牙科醫生	Dr. Sandra Lee	牙醫顧問	Dental Advisor
徐伯鳴、陳鴻遠、	Chui & Lau Solicitors & Notaries	義務法律顧問	Hon. Legal Advisor
劉永強 律師行	Chan & Lau Johntons & Notaries	かいハハム 十一氏ニリ	Hon. Logal Advisor
譚根榮會計師行	K.W.Tam & Co. C.P.A.	義務核數師	Hon. Auditor

## 執行委員會 Executive Committee

梁建文先生	Mr. Leung Kin Man, Michael, MH	主席	Chairman
唐許嬋嬌女士	Mrs. Heidi Tong	副主席	Vice-chairman
江馬玉琴女士	Mrs. Kong Ma Yuk Kum	田立工小り	vice chairman
羅明輝博士	Dr. Law Ming Fai, Ben	義務秘書	Hon Secretary
葉偉明先生	Mr. Yip Wai Ming, Patrick	義務司庫	Hon Treasurer
楊映梅女士	Ms. Yeung Ying Mui, Maggie		
嚴鳳嬌女士	Ms. Yim Fung Kiu		Member
左偉興先生	Mr. Keith Chor	委員	
馮逸生先生	Mr. Fung Yat Sang, Patrick		
劉蘇敬順女士	Mrs. Lau So King Shun		
李子超醫生	Dr. Lee Chi Chiu		
李小珍女士	Ms. Lee Siu Chun, Daisy		
李建賢博士	Dr. Li Kin Yin, Mark		
王慶馨女士	Ms. Wong Hing Hing, Frazer		
	Mrs. Junko Sommerau		

#### 財務委員會

#### **\ Finance Committee**

馮逸生先生	Mr.Fung Yat Sang, Patrick	主席	Chairman
姚榮輝先生	Mr.Yiu Wing Fai, Kenneth	副主席	Vice-chairman
梁建文先生	Mr. Leung Kin Man, Michael		
葉偉明先生	Mr. Yip Wai Ming, Patrick		
王慶馨女士	Ms. Wong Hing Hing, Frazer	委員	Member
劉蘇敬順女士	Mrs. Lau So King Shun		
陳慶年博士	Dr. Chan Hing Lin		
莫關雁卿博士	Dr. mok Kwan Ngan Hing, Edith		

#### 服務委員會

#### **\ Services Committee**

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李子超醫生	Dr. Lee Chi Chiu	副主席	Vice-chairman
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林詠珊小姐 Ms. Lam Wing Shan

年度亮點 HIGHLIGHTS OF THF YFAR

# 第十二屆世界唐氏綜合症高峰會 The 12th World Down Syndrome Congress Let's Make an Inclusive Tomorrow

第十二屆世界唐氏綜合症高峰會於2015年8月19日至21日於印度清奈舉行,本會是次派出三名職員及一名執行委員會代表出席是次會議。是次會議主題為「Let's make an inclusive tomorrow」期望透過不同國家及界別的分享,使唐氏綜合症人士的生活質素有所提升。會議亦主要討論唐氏綜合症人士的五個範疇:社會意識及自決、健康、教育及就業、支援系統、權利和法律。

透過同工的分享,會議給予機會去讓大家反思現行服務,也給予大家一個嶄新的思維去策劃不同服務模式。會議中,唐氏綜合症朋友被稱為「Self Advocator」,翻譯為中文是「自我倡導者」。一直以來,香港政策對於殘疾人士主要以提供服務為主,鮮有倡導成份。但在會議中看到不同國家的唐氏綜合症朋友,無論是發展中國家,還是發達國家,他們的參與者均擁有強大的倡導能力。無論在工作上、學業上、事業上也十分相信自己的能力,甚至能夠為發展社區出一份力。這種程度的社會參與、與不同持份者的溝通,以及自我倡導的精神十分值得我們效法。

另讓唐氏朋友表達自己的機會亦為深刻,即使他們有些口齒不清,有些則口才了得,最特別之處是他們準備了關於自己故事的簡報,內裡充滿他們的相片、片段及文字介紹,使參加會議的人都清楚明白他們想表達的訊息。反思香港有部份同工或家長會擔心唐氏綜合症人士如何表達自己,怕他們在公眾場合會說錯話,這也間接地剝削了他們表達自己意思的機會。





會議中有來自澳洲的E.motion21,他們是一個為唐氏綜合症人士提供健體及舞蹈活動的國家,他們的舞蹈經不同研究而設計出來,而在設計上亦考慮到唐氏綜合症人士是否玩得開心,能夠欣賞一場又齊整又華麗的演出外,亦見大家相當投入開心。

也許唐氏朋友擁有獨有的「親和力」。同工能與他們談論著電影、工作。事實上,唐氏朋友們都有長大的一天,過份保護也許令「小孩子」學不會長大。憶述會議中一位講者抱著一個信念「唐氏人士天生獨有比一般人強的天賦能力」。換個角度,我們有很多事需要向唐氏朋友學習。我們或者無需強迫整疾人士改變自己來迎合社會;反而我們要更努力改善表情讓殘疾人士過更好的生活。

The 12th World Down Syndrome Congress was held from 19 to 21 August 2015 at Chennai, India, and the Association nominated 3 staff members and 1 Executive Committee member to join. The theme of the Congress this year was "Let's Make an Inclusive Tomorrow", signaling the hope that the quality of life for people with Down Syndrome could be improved through shared experience from different countries as well as from different fields. A few main topics were discussed during the Congress, including: "Social Awareness & Self-Determination", "Health, Education & Employment", and "Support System, Rights and the Law".

宇一位
From the experiences shared between participants, the meeting gave us a chance to review our current services and a new and different way of planning out our service model. We were most impressed by the name the organizers gave to people with Down Syndrome: they were not only known as "People with Down Syndrome", but also as "Self Advocators". This is important because in Hong Kong, organizations are usually service-oriented but seldom advocate for their users. In this Congress, I met many people with Down Syndrome from different countries, both developed and undeveloped countries, but all were strong advocators. No matter in their work, schooling and careers, they all believed in their ability to make a contribution to the community. Such a level of social participation, stakeholder communication and self-advocacy is worth considering in our daily line of work.

The self-expression of Down Syndrome participants also left an impression on me. A few people with Down Syndrome shared their stories onstage: although not every presentation was polished, the many photos, clips and wordings included in their PowerPoints meant that all participants could clearly understand their messages. In Hong Kong, a few colleagues or parents worry that people with Down Syndrome don't know how to express themselves – "What if they say the wrong things?" "What if nobody understands them?" – and indirectly, it seems that such well-intentioned moves might actually deny their right to expression.

We also got to enjoy the Australian group E.motion21, who organize fitness and dancing activities for people with Down Syndrome. With dance moves that are specially-designed around the user's capabilities as well as enjoyment, we were able to witness a wonderful performance that everybody appreciated very much.

Perhaps this is the famous intimacy of people with Down Syndrome, which presents itself no matter the country... we talked happily with them about movies and work. Sometimes we treat people with Down Syndrome beyond the level of kids, no matter how old they actually are; but in reality they will grow up one day, and ignoring that fact and over-protecting them might not be the best way to go. Yes, too much alcohol is not good for them, but so is the failure to learn lessons about personal responsibility. During the Congress, one scholar held a belief that saw people with Down Syndrome having "unique and better talents" compared with ordinary people: from another perspective, we do have a lot of things we can learn from them. Perhaps forcing disabled people to adapt to our society is the wrong way to go: rather, we might have to work harder in order to create the conditions where people with disabilities can have a better life.

## 2016年2月13日(星期六)全港賣旗日藉旗子送上祝福

## HKDSA Territory-wide Flag Day 13.02.2016 Giving for Blessings

協會於2016年2月13日(星期六)於全港各區舉行賣旗籌款活動,是次活動 共招募了近1700名義工,籌得善款港幣約106萬元。協會能有此佳績, 實有賴各學校、團體、會員及義工的鼎力支持。

今年賣旗日適逢農曆新年期間,邀請本會副會長劉嘉玲小姐擔任祝福 大使,以行動支持賣旗日。此外協會更特意設計12生肖旗子套裝,旗子印





#### 年度亮點 **HIGHLIGHTS OF** THF YFAR

## 3.21世界唐氏綜合症日 3.21 World Down Syndrome Day

聯合國大會宣布由2012年起,3月21日為世界唐氏綜合症日,以提高公眾 意識並倡導唐氏綜合症人士的權利。在世界唐氏綜合症日,世界各地都 有不同的精彩慶祝活動,以喚起大眾對唐氏綜合症人士的關注。

香港唐氏綜合症協會為2016年世界唐氏綜合症日定出年度主題—「健康」, 在3月份一連兩個週末、日舉行兩項大型活動。對於唐氏朋友及照顧者本身, 健康關注是何等的熱切。因此,協會於3月13日假東華學院舉行「健康 普查日 | 以提升唐氏、智障人士、其家長及公眾人士對健康的關注。當日 大會提供一站式的健康檢查及評估,除了簡單身高體重、血壓測量之外, 還有心臟、骨質疏鬆檢查、失智症評估等等。又提供不同主題的健康 講座,包括:精神科、心臟科、骨質疏鬆、牙科、中醫食療。目的讓唐氏或 智障人士及照顧者了解自己的身體狀況,尤其是家長,他們往往忽略自身 的需要!協會亦派發早前與明愛醫院李靜賢醫生合著出版唐氏人士健康 紀錄手冊,提供指引及提醒照顧者在唐氏子女不同成長階段,應做適時的 健康檢查及跟進。大會當日亦安排冥想放鬆練習及健體活動,有助一眾 參加者學習保持良好的心理及心靈狀態,這才是全人健康關注。

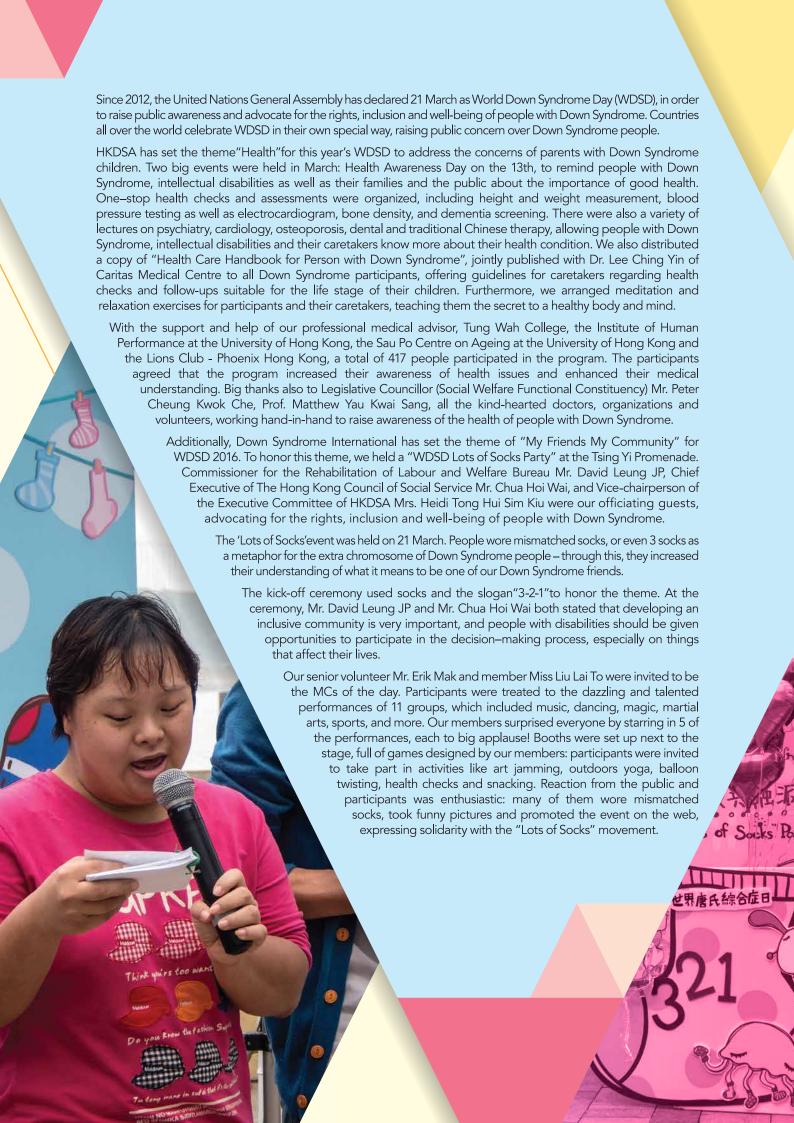
「健康普查日 | 活動當日共有417人士出席, 參加者均表示活動能提昇 他們對健康的關注及增加健康資訊。是次健康普查日由本會專業醫 學顧問及獲東華學院、香港大學運動及潛能發展研究所、香港大 學秀圃老年研究中心及鳳凰獅子會支持協助。更感謝張國柱議 員的來臨、邱貴生教授的支持及借出場地,各位有心醫生、團體 的支持、義工朋友的協助,攜手一齊去提升會員及公眾人士對

唐氏及智障朋友的健康關注,實在難得。 此外,為響應2016年世界唐氏綜合症日的主題一「我的 朋友 我的社區」(My Friends, My Community),協會於3月 19日下午假青衣海濱公園舉行「親朋『襪』友共融派對」, 邀請勞工及福利局康復專員梁振榮太平紳士、香港社會服務 聯會行政總裁蔡海偉先生及香港唐氏綜合症協會執行委員會 副主席唐許嬋嬌女士蒞臨主禮,藉此鼓勵唐氏綜合症人士共同 倡議自身的權利,同時喚起公眾人士對唐氏朋友及其他殘疾人士 的關注以及建立共融社會的重要性。其實,於3月21日這個世界唐氏 綜合症日,不少國家舉行名為[Lots of Socks]活動,以襪作為標記, 當日穿上兩隻不同的襪子,甚至穿上3隻襪子,用以比喻唐氏朋友的3條 染色體,藉此引起社會對唐氏綜合症人士的關注,增加對唐氏朋友的認識。

派對啟動儀式亦同樣以襪及321為標記以呼應主題。於典禮上,勞工及福利 局康復專員梁振榮太平紳士及香港社會服務聯會行政總裁蔡海偉先生,大家 均表示締造一個共融平等的社區是非常重要,社會上每個人都需要被接納同 尊重。而一班唐氏綜合症人士或其他殘疾人士在平等的基礎下,應與一般人士同樣 享有充份的機會和平等的權利去參與生活上各項的決定。

派對邀請了本會資深義工麥嘉緯先生及會員廖麗圖擔任大會司儀。派對活動非常 豐富,共邀請了11個團體表演,包括音樂、舞蹈、魔術、武術、體育等不同項目。其中5個 更由本會會員親自上陣,令人驚喜之餘亦見觀眾投入欣賞。台下還有多個豐富攤位,包括 當中由會員策劃的攤位遊戲、扭波、即興藝術創作、健康資訊、親子瑜伽及小食等等,不同 團體和大眾一齊參與,不少參與者亦同樣穿上兩隻不同的襪子以響應 [Lots of Socks] 活動,更在網上推廣,公開其有趣「襪照」。





研究及倡議 **RESEARCH & ADVOCACY** 

#### 唐氏綜合症會員需要及家屬身心健康指數 新聞發布會

## Press Release on the Needs of DS People and the Mental **Health Condition of Caregivers**



據政府統計報告,現時本港有 智障人士約7萬至10萬,但有關 唐氏綜合症的統計數字,即沒有; 再者,對唐氏綜合症人士的服務需 要或家庭狀況的調查更缺乏。香港 唐氏綜合症協會一直致力關顧唐氏 綜合症人士及其家庭的需要,協會於 2014年與香港大學社會工作及社會行政系 羅明輝博士合作,進行一項調查,探討唐氏綜 合症會員及家庭需要。此項調查為全港首個大 型調查,並於2015年6月11日舉行唐氏綜合症會 員需要及家屬身心健康指數新聞發布會,探討現有 服務的不足,以提出政策或服務建議。

調查以問卷形式訪問231名唐氏綜合症會員及其家屬, 以了解他們的身心健康及其需要。調查發現,現時超過9 成的會員居於家中,家長或監護人面對著不同的挑戰,如 子女健康及醫療問題。當中有逾七成會員需要定期覆診或看 醫生,逾3成更需長期服藥,家長則面對經濟壓力。此外,社交、 未來出路等子女的成長所需要問題均是家長或監護人較為關注。 香港大學社會及社會行政學系助理教授羅明輝博士指出受訪的 照顧者呈現不同程度健康及情緒問題、憂鬱、自尊感較低,近3成表示 有健康問題,當中有近1成表示有中度至嚴重憂鬱。羅博士更指未成年 的會員家長或監護人呈現上述問題的比例更高於成年會員。

協會總幹事楊冰梅女士指出,9成多的會員與家人同住,其家長或 監護人在唐氏綜合症人士的生活及照顧上擔當非常重要角色,家長 或照顧者為中年女性為主,大多放棄就業,故建議立法保障照顧者, 設立照顧者津貼、醫療及交通津貼等支援,津貼亦是為他們充權, 肯定她們付出及讓他們有能力去購買社區上不同的服務,同時亦鼓勵 其他成員分擔照顧者的責任。總幹事更指出香港針對唐氏綜合症 人士需要的服務仍有不足,年滿18歲的唐氏人士便被轉介到一般 的成人診所,相對而言,這群醫生對唐氏綜合症人士的認識未 必深入,了解他們的需要和溝通技巧往往需要時間,加上近年 智障人士老齡化問題值得關注,建議增加醫護人員培訓及 設立成人唐氏綜合症人士診所,以及早和作出針對性的 醫療性服務。家長或監護人對子女的教育及成長階段 需要尤其關注,協會推展短期創新及針對性的家庭 服務,協助懷有或初生唐氏小孩的家庭,提供輔導 及早期訓練,以正視這班未成年組別的需要。唐 氏綜合症人士需要及早和充裕的訓練和學習 機會,只有透過不斷的學習,才能使他們健康 愉快地成長。協會現自負盈虧籌募經費支 持的唐家軒,定期提供不同類型的發展 性、才能培訓和成長的課程,是本港唯 --間專為唐氏朋友而設的中心 , 盼服務能獲政府資助, 正視

他們的需要及撥款支持。



According to government statistics, there are around 70 – 100 thousand people with intellectual disabilities, with no figure on people with Down Syndrome. In Hong Kong, there is a lack of information on the needs of people with Down Syndrome or of their families either. Therefore, the first large scale survey was conducted collaboratively with Dr Ben Law, Assistant Professor of Department of Social Work and Social Administration of the University of Hong Kong, and the Hong Kong Down Syndrome Association at the end of last year. A press release on the Needs of DS People and the Mental Health Condition of Caregivers was held on 11 June 2015 in order to reveal the results and provide suggestions based on them.

Questionnaires were collected from 231 members with Down Syndrome as well as their families regarding both their physical and mental health as well as their needs. The survey found that there are more than 90% of members living at home, while the parents or caregivers face different challenges, such as worrying about the health and medical issues of their child. The report found that more than 70% members have regular medical follow-ups and more than 30% need long-term medication – economic stress is therefore an issue as well. Social life and future development issues are also issues of parental concern. Dr. Ben Law, noted that caregivers who were interviewed showed various degrees of health and emotional problems, such as depression and low self-esteem; more than 30% expressed some health problem and nearly 10% expressed moderate to severe depression. Dr. Law also found that the percentage of parents suffering from the above problems is higher among the group of Down Syndrome members aged under 18 than those of adult members.

Ms. Maggie Yeung, Director of the Hong Kong Down Syndrome Association (HKDSA) stated that parents or caregivers of people with Down Syndrome play an important role in the family as more than 90% of members are living at home with their parents. According to this survey, the main caregivers are women of middle age and are not engaged in the workplace. Yeung suggested that the government should recognise their contribution and provide them with carer's allowance, medical, transportation allowance and so on, as it is an effective way to empower them and gives them the resources to obtain quality services. Ms. Yeung also stated that there are not enough specialized services for people with Down Syndrome in Hong Kong: for example, DS people at 18 or above would be referred to a general adult clinic, where doctors might not have a good understanding of their needs and characteristics, requiring more skill and time for effective communication. With the aging problem of people with Down Syndrome, enhancing the training of medical professionals, as well as setting-up an Adult Down syndrome Clinic is suggested.

As shown in the survey, parents and caregivers place a high focus on their children's education and development. HKDSA has launched a time-limited but specialized family-supported service project to provide pre-natal counseling and support service to both parents-to-be and parents with Down Syndrome babies. We aim to provide appropriate training at an early stage so that people with Down Syndrome can live happily and independently. Also, our DS Centre located at Wanchai is a self-financed service dedicated to serving people with Down Syndrome, offering various training and interest classes as a means to unleash their innate talents. Yeung hoped that the government could recognize the needs of people with Down Syndrome and their families, and provide sponsorship and support to the service.

友好伙伴 PARTERSHIP

#### 香港女子俱樂部一游泳馬拉松

## Ladies Recreation Club - Swimathon 2015



2015年4月18日(星期六),再度獲得香港女子俱樂部(Ladies Recreation Club)的熱心支持,為協會舉辦游泳馬拉松籌款活動。當日協會共派出2名教練及11名泳隊隊員参與,而Ladies Recreation Club派出超過60名來自該會不同游泳級別的健兒参加這次「游泳馬拉松」活動。每組参加者都非常努力地在1小時內去完成整個活動,過程中参加者彼此互相認識及學習,一同分享游泳心得。本年度之「游泳馬拉松」活動為本會所籌得善款超過14萬,用作資助協會游泳運動發展項目,希望透過游泳訓練發揮會員的運動潛能、提升自我形象及培養健康的生活方式。

HKDSA thanks the Ladies' Recreation Club for once again supporting and inviting us to join the LRC Annual Swimathon on Sunday, 18 April 2015. 14 HKDSA representatives, including 11 swimmers, 2 coaches and a team captain joined the event, and more than 60 LRC members showed their support by making a per lap pledge. More than HK\$140,000 was raised, with funds going to support the development of swimming activities by HKDSA. Through swimming, we can unleash the potential of our members, as well as promote healthy lifestyle and self-regard.



#### 偷景灣康樂會 第12屆慈善網球賽

## The 12th Discovery Bay Recreation Club Charity Tennis 2015



2015年10月10日(星期六)協會欣喜能繼續參與由愉景灣康樂會所舉辨之第12屆慈善網球賽,更成為其中一位受惠機構。衷心感謝各網球隊伍在網場上為慈善奮力拼搏,同時亦多謝各義工朋友、志願者及來實參與協助草地嘉年華的攤位活動,將愛與關懷傳遞出去。協會Island Dance成員在在網場上落力演出,精彩的舞蹈表演為活動添上活力,亦讓參加者看到唐氏綜合症朋友的才能。大會在傍晚舉行晚宴及支票頒贈儀式,而晚宴更設有拍賣環節,各善長的熱心慷慨,為協會籌得超過16萬的善款。

On 10th October (Saturday), HKDSA was pleased to continue its participation in the 12th Discovery Bay Recreation Club Charity Tennis 2015 as well as being one of the beneficiaries. We sincerely thank all tennis teams who battled it out on the courts for charity that day! We would also like to thank every volunteer for helping and attending the court-side family carnival, especially our Island Dance Team, whose great performance not only created an energetic atmosphere, but also showed the talents and potential of people with Down Syndrome. The Dinner cum cheque presentation ceremony was held in the evening, including an auction round. Counting all contributions and unfailing support from our donors, more than HK\$160,000 was raised for HKDSA.

#### 「亮睛睛」眼科檢查計劃

## A Wonderful World – Vison Health Project

為鼓勵會員進行眼科檢查,協會推行「亮睛睛」眼科檢查計劃,目的除鼓勵會員接受眼科檢查,更重要是提升家長和會員對眼睛健康的知識和意識計劃。此計劃更喜獲研達企業有限公司及兩位善長Mr. Thomas Wee及梁健文先生支持。2015年11月6日,協會為計劃掀起序幕,舉行了一個簡單而隆重的支票送贈儀式,以感謝公司及善長的慷慨支持。

是次計劃,協會與香港盲人輔導會合作,由該會眼科視光師為年滿18歲的會員檢查眼睛。 如初步診斷需由眼科醫生跟進,視光師將轉介予該會眼科醫生。

In order to encourage members to go for eye check-ups, HKDSA launched "A Wonderful World – Vison Health Project". The aim of the program is not only to increase the number of members having proper eye examinations, but also to raise awareness and knowledge amongst parents and members about the importance of eye care. This year, we have also been honored with donations from Novation Solutions Limited, Mr. Thomas Wee Soon Thong and Mr. Michael KM Leung. On 6th Nov 2015, HKDSA held a simple but momentous cheque presentation ceremony in order to show our sincere appreciation.

For this program, HKDSA is partnering with the Hong Kong Society for the Blind: all members aged 18 or over have the opportunity to undergo eye check-ups by the HKSB's resident optometrist. If initial diagnoses require a more in-depth investigation, cases will be transferred to the HKSB's resident ophthalmologist.



友好伙伴 PARTERSHIP

#### 的近律師行─聖誕童騎樂

## Deacons - Riding for KIDSmas



九龍金域扶輪社 周年聖誕派對

## The Annual X'mas Party of the Rotary Club

2015年12月23日,本會喜獲九龍金域扶輪社的邀請, 數10位唐氏綜合症的朋友及其家人參加九龍金域扶輪社 於尖沙咀金域假日酒店舉行的周年聖誕派對。當日各唐氏 綜合症朋友都施展混身解數,唱歌跳舞、演奏小提琴、耍太 極及唱粵曲,為派對及來賓帶來一個個精彩的表演,盡見他們 的創意及才藝。

On Dec 23, several Down Syndrome children and their relatives were invited to join the annual X'mas Party of the Rotary Club of Kowloon Golden Mile at the Holiday Inn Golden Mile, Tsim Sha Tsui. It was a wonderful stage on which members demonstrated their fantastic ability in performance, dancing, singing, playing violin, Tai Chi and even Cantonese Opera: everybody agreed that the event fully showcased their creativity and talent!

的近律師行過往一直都全面支持愛心聖誕大行動,於2015年12月19日,其愛心熱心繼續延續,與香港傷健策騎協會有限公司合作,贊助愛心聖誕大行動的受惠機構參加了一個別開生面的活動 - 聖誕童騎樂。

9位年齡由9至18歲的會員獲邀參與活動。活動於香港賽馬會屯門公眾騎術 學校舉行,20位來自的近律師行的義工負責帶領會員共同享受一堂策騎 課堂,會員均展現出充滿自信的笑容,實在是一個美好而有趣的體驗。

Deacons has given its full support to 'Operation Santa Claus' for the past few years and their enthusiasm continues to grow. On 19 December, Deacons collaborated with the Riding for Disabled Association (RDA) to bring our members, who are beneficiaries of OSC, to bring them a special Christmas gift - "Riding for KIDSmas".

9 members aged 9 to 18 were invited to join the event: you could see the confident smiles on their faces when they interacted with those black and white ponies! Thanks to the 20 employees from Deacons for guiding members throughout an enjoyable riding lesson at the HKJC Tuen Mun Public Riding School – we are sure both sides had a fun and memorable experience!



#### 荷花集團2016「BB春季購物展」暨 「兒童成長教育展」

## Eugene Group 2016 "Baby Show in Spring & Child Growth Education Expo"

協會獲選成為由荷花集團舉辦的2016「BB春季購物展」暨「兒童成長教育展」的受惠團體,獲贊助港幣HK\$20,000,作為購買「甜心學堂」之教材,教材可供在導師的指引下借出予服務使用者,有助加強早期介入的訓練。協會更免費獲贈慈善攤位一個,於展覽期間作為推廣及籌款之用,共同為孩子的健康快樂人生努力。

The Association was chosen as the beneficiary of the 2016 "Baby Show in Spring & Child Growth Education Expo". Eugene Group graciously sponsored HK\$20,000 towards purchasing training tools for our "SweetieLand" service. These training tools can be lent to service users under trainer supervision, for the purpose of increasing the effectiveness of early intervention training for children. The Association also was the recipient of a sponsored charity booth for promotion and fundraising purposes for the duration of the Expo, assisting in its mission to bring happiness to all children.



媒體報導 **PRESS** 



#### 香港電台 第五台 **RTHK Radio 5**

有你同行





#### 香港電台 第一台 **RTHK Radio 1**

非常人物生活雜誌



#### 唐氏症照顧者呈健康情緒問題

香港唐氏綜合症協會去年進行全港首 個大型調查,以問卷形式訪問231名唐氏綜 合症會員及其家屬·以了解他們的身心健 康及需要。結果發現,逾九成會員居於家 中,家長或監護人面對不同的挑戰,如子 女健康及醫療問題,當中七成需定期覆診 或看醫生,逾三成需長期服藥,家長則面 對經濟壓力。負責研究的港大社會及社會 行政學系助理教授羅明輝指出、受訪的照 顧者呈現不同程度的健康及情緒問題,如

憂鬱、自尊心較低。 該協會總幹事楊 冰梅(圖)指出,家長或 監護人在唐氏綜合症人 士的生活及照顧上擔當非

常重要的角色・且多是中年女性・大多放 棄就業,故建議立法保障照顧者,設立照 顧者津貼、醫療及交通津貼等支援,肯定 她們的付出及讓他們有能力選擇社區上不 同的服務,減輕照顧壓力。





#### E周刊 E Media

You're so beautiful









#### Carers of Down syndrome sufferers seen to pay high price

The survey drew on 231 parent-members of the association. More than half of their Down syndrome children are aged from 18-30, about 30 percent under 18 and the remainder from 31 to 51. Ninety percent of sufferen five with their families. Association director Maggie Verung Ying-mia and government officials have overlooked the needs of Down syndrome patients and their carers. Most caren are middle-aged mothers who have quite carers to look after their children, also said. A managem—mares or social workers—to help Down quite carers to look after their children, also said. A real size suggested the setting up of a clinic for cares to congrue their efforts.

Medical and transportation assistance for carers Medical and transportation assistance for cares.



中環馬引

頭條日報

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唐氏綜合症人士

的共融小團隊

ET IMAY





社企

#### 佛門網 **Buddhistdoor**

時事脈搏

香港唐氏綜合症協會 HKDSA

較早前,協會的唐氏專劇團接受了有線電視節目「至Fit男女」的訪問,當 中不難看得到各人的努力,他們的能力及單純的堅持,同樣能演出幕幕精 彩人生,赢得我們的堂聲

Our DS Cantonese Opera Group accepted the interview from Cable TV pgm. All their efforts and passion have been fully shown, they can all enjoy their fruitful and meaningful life. Big Applause to them......



時事脈搏

2016-03-21

唐氏綜合症日:一雙腳,三隻襪.與唐氏朋友同行

一雙維穿三隻襪,怎樣表達庸氏綜合症人士的特徵?

由2012年起,聯合國把今天(3月21日)定為世界唐氏 综合症日,希望提高普羅大眾對唐氏綜合症的認識及關 注。今年的主题為「我的朋友,我的社區」(My Friends, My Community),用意是希望唐氏綜合症朋 友融入社會,像普通人一樣生活。

上周六(3月19日),香港唐氏綜合症協會在青衣海濱 公園舉行「親朋『嶺』友共融派對」,以嘉年華會形 式,安排了不同表演、變位遊戲、親子瑜伽活動等等 吸引一家大小及不同團體齊來參與,場面熱鬧。不少參 加者更脱去鞋,露出腳上穿著的兩隻不同額色機子拍 照,借此響應不少國家在唐氏綜合症日當天學行的 「#Lots of Socks」活動—活動以機作為標記,呼輸各

位在今日穿上兩隻不同的襪子,甚至三隻襪子,以此比 **岭唐氏朋友的三條染色體** 1 ,引起社會對唐氏綜合症人士

的關注,增加對他們的認識。

現場所見,很多朋友一起拍攝有趣的舉腳「機關」,更 即時上傳網絡平台,讓更多人知道這項有意義的活動。 正如香港唐氏綜合症協會執行委員會副主席唐許娛媽女 士在活動上表示:「希望藉著今日的活動,讓唐氏綜合 症人士及其他殘疾人士從中感受被接納、認識更多朋

友,建立友誼。相信有助他們在日後生活及工作上更有 自信和自主性、更能融入社會。」

派對雖然已興滿結束,但香港唐氏綜合症協會呼籲各位 有心人,可繼續將「機熙」上傳至Facebook或 Instagram,向身邊朋友分享「著鴛鴦樓」的原因,藉 此帶出我們跟唐氏朋友或許有些地方不相同、但彼此也 是社會一份子的平等信息:大家可以互相配合,共同合 作,建立一個共融社會。

香港康氏総合症協會Facebook專頁: https://www.facebook.com/%E9%A6...71905/

1 一般人名假细斯有四十六條染色體,而接近百分之九十五的唐氏综合症人士在第一十一對染色值上多了一樣,要如如解有四十一條次色體,這條多了出來的,除 公律。









有線電視 i-Cable 至Fit關懷



**World Down Syndrome Day 2016** My Friends My Community短片











圖文傳真 Fax

## 香港唐氏綜合症協會 The Hong Kong Down Syndrome Association

出版 香港唐氏綜合症協會

Published by The Hong Kong Down Syndrome Association

2016年12月 出版日期 Publishing Date December 2016

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