



# International Stuttering Association

*A World that Understands Stuttering*

To: International Stuttering Community  
From: Michael Sugarman, Chair  
Regarding: June 2012 eNewsflash

## Chair's message

Enjoy your moments with your ---soul mate,  
children, family and friends...

Wednesday night May 23rd, Kim (my wife) and I attended President Obama fund raiser in Silicon Valley, California. Kim was walking downstairs at the Fox theatre in Redwood City and fell. Her body hit a cement barrier and twisted and laid flat on her back. She had a seizure. Paramedics and Secret service agents rushed to her. I sat holding her hand and massaging left shoulder.

She sped away to Stanford Emergency Dept. Hospital in Palo Alto. The ambulance/ paramedics did not allow me to ride with her. My car was parked four blocks away. I ran toward my car. I was stopped by four police officers. Five minutes later with assistance from secret service and police officer from the fox theatre, I was released.

Kim was in ICU and later transferred to intermediate care ICU and finally to the regular hospital floor. She was discharged on May 28th.

She is home recovering with hairline neck fracture, severed liver and cracked ribs.

I thought I lost her...I asked her not to leave me. I would be helpless without her. Besides I would not know how to raise our 21 year daughter.

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# One year to go to the World Congress 2013



**FIRST ANNOUNCEMENT**

## **10th World congress for People who Stutter**

Lunteren, The Netherlands

Monday 10 – Thursday 13 June 2013

**Conference title:**

'Hear no evil, see no evil, speak no evil:  
Breaking taboos around stuttering'

**Hosted by:**

The Netherlands Stuttering Association Demosthenes

**Location:**

Congresscentre 'De Werelt', Lunteren

Objectives of the congress:

- to connect people from all over the world who share the same speech impediment
- to share knowledge, scientific and other, about stuttering with each other
- to share this knowledge with the world, to help others who don't have any resources

### Themes / sessions:

New developments & research, personal stories, communication, treatment & therapy, education & work, taboo-breakers, parents, children and school

This congress is for:

- people who stutter themselves
- their families and friends
- therapists and students in speech pathology

Call for Papers opens June 1st. For more information, visit our website [www.stuttering2013.com](http://www.stuttering2013.com)

### Organization committee:

- Chair: Maartje Borghuis
- Treasurer/secretary: Patrick Wetzels
- PR and technical support: Richard Bourgondien and Marloes de Jong

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Below is a draft to change the current constitution which can be found on the website. Please send me your comments.

Take a look at the article: [Administrative Pronouncements and Interpretations of the constitution by the ISA Board](#)

1 Constitution paragraphs about 'payment of membership fees'.

- Every association will be invoiced every year.
- There are circumstances where a member association may ask to have regular fees, or a variable annual donation, waived.
- Associations that make payments will be allowed to nominate representatives to stand for election to the ISA Board of Directors.
- Associations that make no payments may not nominate representatives to stand for election to the next ISA Board.
- All other member rights will be available to all member associations.

## 2 Constitution paragraphs about 'membership meetings and World Congress every 3 years'

- There is a three yearly cycle of membership meetings and World Congress. This cycle has evolved over time and in part is based on other meetings of other organizations in the world of stuttering. (cycle, 2001, 2004, 2007,2010, 2013, 2016 etc.)
- If an Association has approval to hold the next World Congress, but is unable to do so, then other associations will be requested to step in.
- Due to timing, this may invalidate, for one year, the three yearly cycle.
- The following World Congress will return to the original stated three yearly cycle.

## 3 Constitution paragraphs about 'terms of office'

- A term of office on the Board of Directors is usually three years.
- In unusual circumstances there may be a different length of office, if the time between the next membership meeting and World Congress and the last membership meeting and World Congress is not three years. In which case, a term of office may be 4 years followed by 2 years. In either case, a director may be nominated for the next 3-year term provided the director does not exceed the 9 year limit (see number 5 below).

## 4 Constitution paragraphs about 'Proxy votes'

- Any Member Association who cannot attend the membership meeting may ask any other voting attendee to vote on their behalf.
- A copy of the request must be shown at the membership meeting.
- The request will make clear if the attendee can use the proxy as they wish for all votes, or if there are particular issues where a specific vote is required.

## 5 Constitution paragraphs about 'the length of time a person may serve on the ISA Board as a Director'.

- Any person may serve a maximum of 9 years in a decision making role for the ISA since 1995.
- The period of time may be consecutive or non consecutive years / terms of office.
- When their time is complete, or earlier if they do not want to serve a full 9 years, they may ask to serve on the Advisory Board (see below).
- If, because of unusual circumstances (see above) a person has served for 7 or 8 years, they may not stand for re-election if the next term of office will take them over the maximum of 9 years.
- If the current 'term of office' (see above) gets extended, they may remain on the Board until the next membership meeting and elections.

## 6 Constitution paragraphs about 'Associations representation on the Board of Directors'

- Ideally there will be 9 different associations represented on the Board Directors.
- At the membership meeting at least 5 approved nominations, up to a maximum of 9, may be elected to serve on the Board after verbally agreeing to work a few hours a month on ISA business.
- If possible (5 nominations must be elected) there will only be one representative per association.
- If there is a second approved nomination by one or more associations, these names will be held in reserve for possible use.
- If there are fewer than 5 associations with approved nominations then names in reserve may be used to make a minimum of 5.
- If necessary, during the first 3 months of office, the Directors will seek to bring their numbers up to 9, including the use of any unused reserved names.
- The Board of Directors will seek ways to maintain their numbers at 9. To do this, the Board might consider, but would not be limited to
  1. Asking specific Associations for a nomination,
  2. Asking an Advisory Board member (care needed on number of years service in office),
  3. Asking Special Friends,
  4. Asking Associations to advertise a vacancy in their magazines / websites.

## 7 Constitution paragraphs about 'board members representing their own associations, not themselves'

- From time to time an association may remove its support from a Board Director, for example if the Director does spend time helping the ISA.
- If this happens, the Director may consider stepping down from the Board.
- However, a Director is elected for the term of the Board (usually 3 years). If the local association withdraws support, then that Director may remain as a Director to complete the term, subject to a Board vote, looking at what is best for the ISA.
- If the vote of the Board is to remove the Director, then the Chair will do so by excluding him/her from any ISA email discussion.
- The Board of Directors will seek ways to maintain their numbers at 9.  
(See also para 6.7 above)

## 8 Constitution paragraphs about 'Director's responsibilities'

- Every elected Director will be accountable to both his/her own Association and to the Board of Directors.
- When a Director is elected / appointed to Chair an ISA committee, that Director is

responsible to and accountable to the ISA Board of Directors.

- When a Director writes anything on behalf of the ISA, then it must be approved, and can be amended, by the ISA Board before publication.
- When any Director wants to raise a motion for discussion and a vote, then there must be another Director who will second the motion.
- When standing for election, the candidate should verbally agree to spend a few hours per month on ISA business. If this does not happen, the Chair discuss action with the National Association.

#### 9 The ISA Advisory Board.

- The ISA Advisory Board is a non voting Board set up to help and advise the main ISA Board of voting Directors.
- The Advisory Board is appointed, not elected, by the Chair and ISA Directors.
- Membership of this Board will include, but not be limited to,  
People (professionals or others) who, based on their experience, can help ISA Directors to carry out their objectives;  
Former ISA Directors who have served the ISA well and still wish to serve the ISA.
- Directors or members of the ISA family can nominate anyone to stand for membership of the Advisory Board.
- Nominations, which can also be self nominations, should go to the Chair of the ISA who will discuss the nomination with the Board.
- The main criteria for acceptance of the nominations will be a proven track record and an ability to join a team to help ISA Directors.
- The Chair of the ISA / Directors should review their use of the Advisory Board at least once every term of office.

#### 10. Constitution paragraphs about 'the agenda for the membership meeting'.

- The Chair of the Board may seek advice from any one in the ISA regarding agenda items for the membership meeting.
- Associations may make suggestions themselves (Ideally 2 or 3 months prior to the membership meeting).
- The Chair of the Board, with the help of the Secretary, will circulate a draft agenda.
- The Chair will take into consideration the best interests of all the membership.
- The Chair is solely responsible for the final agenda.
- The agenda will state that people who represent an association at the members meeting will sign a form stating they have the approval of their association to vote.
- It is suggested that delegates who have voting rights at the ISA Membership Meeting bring written documentation, such as a letter or a copy of an email, to the Meeting.

## 11. Constitution paragraphs about 'changes to the constitution'.

- If any member of the ISA, or any Director, or any Advisory Board member, or any Special Friend wishes to make an amendment to the constitution then this should be submitted, with a second named ISA person who agrees, to the Chair of the ISA.
- The Chair will hold a discussion with the constitution committee, which has been set up to deal with these issues.
- The constitution committee will consider,
  - the value of the change to all members;
  - the wording of the change;
  - the pros and cons of a constitution change vs. an interpretation amendment;
  - any issues regarding the ISA's Charity status and USA legal requirements;
  - any other pertinent issues at the time.
- The constitution committee will make a proposal to the ISA Board of Directors.
- The Board of Directors will discuss the proposals and hold a vote.
- If the vote is yes to make changes, the Chair will notify the membership of the agreed proposed changes to the constitution by email. The Chair will request a vote by the membership, as provided in paragraph 11.9 below
- If the vote is no to make changes, the proposer of the change will be advised.
- Boards of all associations will have time to discuss and vote on the change.
- If there is a membership meeting within 3 months, the Chair may consider making the membership vote as part of the agenda, otherwise there will be an email vote.

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# Laws for the benefit of people who stutter

Brazilian Stuttering Association – ABRA GAGUEIRA

Daniela Veronica Zackiewicz  
(SLP, ABRA GAGUEIRA's founder and director)

Roberto A. V. Moraes Filho  
(PWS, Electrical Engineer and Leader of Rio de Janeiro support group – ABRA GAGUEIRA)

In 1999, Mato Grosso do Sul state congressman representative (from Mato Grosso State branch of PMDB party) proposed a telephone fee discount law to people with fluency disorders.

This project succeeded. As a consequence, cell phone companies in Mato Grosso do Sul state should give a 50% discount on telephone fees.

Such a law is also under discussion in other Brazilian states and Brazilian Stuttering Association (Abra Gagueira), as a representative organization for people who stutter in Brazil, has been taking

part on the discussion of the several aspects involved.

Abra Gagueira organization understands that people who stutter and have difficulties on telephone conversation should be eligible to ask for a discount on the telephone fee.

The majority of the people who stutter reports significant difficulties on telephone communication thus showing several speech disfluencies. Such disfluencies which consist of repetitions of sounds and syllables, prolongation of sounds, and blockages of airflow have a significant impact on how long a telephone call last. Besides, the negative experience of the speaker may create fear, embarrassment and avoidance behavior towards the telephone.

The main purpose of such a law must be to financially compensate this extra time spent on the conversation as a result of this communication disturbance.

In order to guarantee that only the person who stutters on the telephone shall benefit, we suggest that speech-language pathologist should give a diagnosis statement on stuttering (CID -10 F.98-5) with a stuttering severity indication under spontaneous speech and telephone speech situations.

In order to obtain people's opinion about this law, ABRA GAGUEIRA opened an online opinion survey (<http://www.abragagueira.org.br/opiniao.asp>). From May 7th to 22th of the current year, 265 people participated, among with: 52% of people who stutter, 38% of language-speech therapists/pathologists, 6% of people who stutter relatives and 4% of people under other conditions. The results showed that 85% of the people who stutter, 87% of the people who stutter's relatives and 74% of the language-speech pathologists approved this law.

Besides this survey, we encouraged discussion through an online forum (<http://www.abragagueira.org.br/forumonline.asp?id=44>). Tenthhs of people adhered.

On May the 30th, ABRA GAGUEIRA's members (Roberto A. V. Moraes Filho, Luiz Fernando S. B. Ramos Ferreira, Renato Poubel and Daniela Veronica Zackiewicz) participated on an audience with the Rio de Janeiro state congresswoman representative Rosângela Gomes.

We agreed to invite another outstanding institution concerned with the stuttering issues, namely, the Brazilian Fluency Institute – Instituto Brasileiro de Fluência, to take part on such discussion, represented by Leila Nagib.

The law project has been forwarded to the Justice and Constitution Committee . At the present time, people who stutter reality in Brazil and their main needs has been discussed.

The next step to be set forth considering this historic moment will be introducing proposals of public policies to support people who stutter and improve their life quality, such as: State Stuttering Awareness Day, Speech Therapy on state health system, Include the discussion on speech disturbances on school program, Stuttering Awareness Week on Schools, State Government counterpart: state taxes deduction on the telephone fees, among others.

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Love to all,



Michael, Chair ISA

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