ALS Awareness in Japan in 2014
Achievements and Difficulties

Japan ALS Association

Yumiko Kawaguchi
A popular actor portrayed an ALS patient on a TV program. We provided script and performance guidance.
Misao Hashimoto and Hiroki Okabe played an important role in “Space Brothers”.
“ice bucket challenge”, raising ¥37,000,000 (about $318,200 USD)
How should we use the funds?

Three Opinions

1, We ought to put it into an external research fund.
2, All the money should be pooled with JALSA’s funds.
3, It would be ok to use the money to run the association.
Achievements in 2014

• We helped younger people/the general public become aware of ALS.
• We received more attention from the mass media than in most years.
• Our membership increased.
• The mood among ALS patients and their families became brighter.
• We received a lot of donations.
Difficulties

We received some complaints about the “ice bucket challenge”

- There is a risk of causing a heart attack.
- It is difficult to refuse to participate once you have been named.
- It is similar to a malicious “chain letter”.
- It is used by celebrities to generate publicity.
- The essence of “awareness” has been lost.
JALSA’s response

• We responded politely to criticisms and questions.
• In some cases people then understood and ended up making a donation.
• We held a press conference on September 2\textsuperscript{nd}.
• We sent an association report to people who made a donation.
• We publicized how the funds raised were being used in our association report and on our website.
Questions for everyone

• After the “ice bucket challenge”, what sorts of activities are needed?
• How should we make use of the list of famous people who made donations?
• What should the funds that have been raised be used for?