

Understanding the Process of the Surrogate Decision Making Committee: Surrogate Decision Making Committee Volunteer Training

Presented by the BAEC Committee for the Disabled, Elder Law
Committee and the NYS Justice Center

January 10, 2019

Welcome and Introduction:

Kelly M. Barrett, Esq., *Chair, Elder Law Committee*
Christopher J. Grover, Esq., *Chair, Committee for the Disabled*

Speakers:

Deirdre Keating, Esq., *Director, Records Management & Access Unit and Counsel to SDMC Program*
Justice Center for the Protection of People with Special Needs

Laura Monthie, BS, RN, LSCW-R, *Director, Surrogate Decision Making Committee Program*

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**Justice Center for the
Protection of People
with Special Needs**

ANDREW M. CUOMO
Governor

DENISE M. MIRANDA
Executive Director

Surrogate Decision-Making Committee Volunteer Training

Agenda

Date: January 10, 2019, 9:00 P.M. – 12:00 P.M.

Presenters: Deirdre Keating, Esq. and Laura Monthie, BS, RN, LSCW-R

9:00pm – 10:00	History and Purpose of the SDMC Program Informed Consent
10:00pm – 10:10	Break
10:10pm – 11:00	Three Decisions Capacity to Consent Authorized Surrogates Best Interest Determination
11:00pm – 11:10	Break
11:10pm – 12:00	Hearing Process Voting by SDMC Panel Objections & Appeals Confidentiality Public Officers Law & Indemnification

Deirdre Keating, Esq.

Deirdre Keating is the Director of the Records Management and Access Unit at the NYS Justice Center for the Protection of People with Special Needs. Among other duties, this Unit is responsible for responding to requests for records and information under various State statutes.

Prior to joining the Justice Center, Deirdre served as a Senior Attorney with the NYS Division of Criminal Justice Services with a primary focus on access to criminal history information issues.

After graduation from Albany Law School and working in private practice, she joined the Counsel's Office of the NYS Department of Correctional Services and worked in the Legislative and Intergovernmental Affairs Unit. She has also served as the Town Prosecuting Attorney for Ravena, NY and the Planning and Zoning Attorney for Rensselaerville, NY.

Laura Monthie, BS, RN, LSCW-R

Laura Monthie is the Director of the Surrogate Decision-Making Committee (SDMC) Program at the NYS Justice Center for the Protection of People with Special Needs. SDMC is a program established by the NYS Legislature in 1988 to provide timely medical decisions for individuals served by the mental hygiene system who lack the capacity to provide their own informed consent and also have no legally authorized and available surrogate to make the decision on their behalf.

Prior to joining the Justice Center, Laura was an investigator for the NYS Commission on Quality Care and Advocacy for Persons with Disabilities. Laura began her career with people with disabilities as a registered nurse and then completed her MSW degree at the University of Albany. She provided advocacy and medical social work services for people with disabilities through early intervention and special education programs, and also residential programs in the Capital District for close to twenty years.



Justice Center for the
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Surrogate Decision-Making Committee for Medical Care and Treatment

CLE and Training for Volunteers
1.10.19

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Agenda

- Surrogate Decision-Making Committee (SDMC)
History and Purpose
- Informed Consent
- Capacity
- Authorized Surrogate
- Best Interests
- SDMC Case Review and Hearing Process



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Agenda (*con't*)

- Common Hearing Issues
- Deliberation and Voting Procedures
- Objections, Denials, and Appeals
- Confidentiality
- Public Officer's Law and Oath of Office

Welcome to SDMC

- Serving on an SDMC Panel enables you to assist New Yorkers with disabilities
- SDMC Volunteers perform a valuable public service
- The SDMC Program staff is here to assist Volunteers throughout the process

SDMC: History and Purpose

Why was SDMC Created?

- Concerns about the care and treatment of people with disabilities were disclosed in statewide public hearings
- Untimely decisions for medical consent through the court system
- Resulted in delays in medical care and treatment

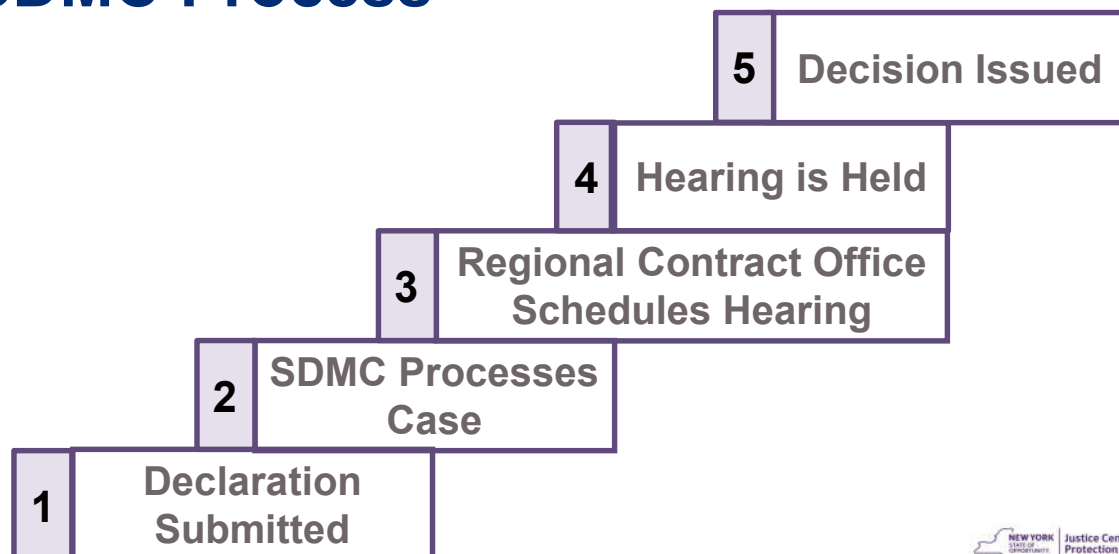
MHL Article 80 and 14 NYCRR Part 710

SDMC

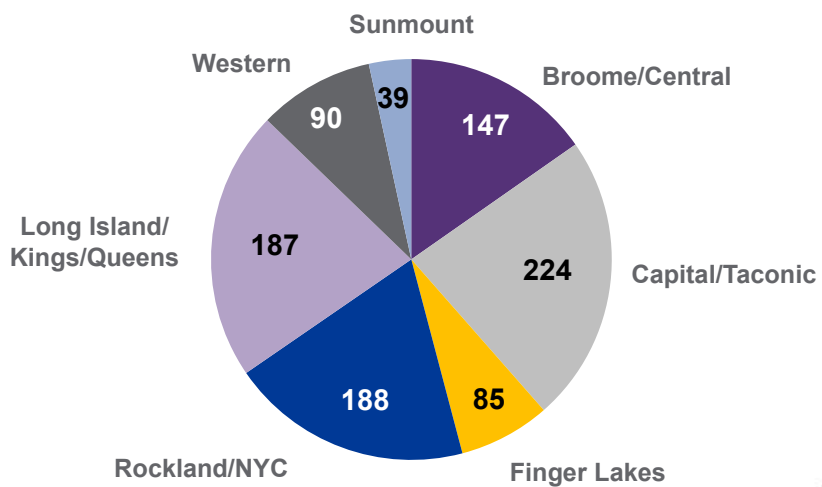
- Cost free alternative to the court system
- Inclusion of the individual
- Timely access to health care
- Due process rights are recognized

MHL Article 80 and 14 NYCRR Part 710

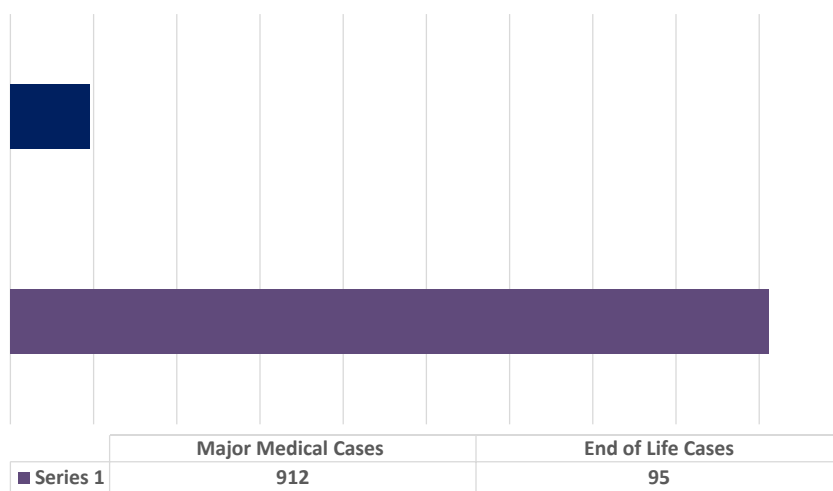
SDMC Process



2018 Cases by Contract Offices



2018 SDMC Case Report (con't)



Mental Hygiene Law § 80.01

Surrogate Decision-Making for Medical Care and Treatment

For persons with impaired decision-making capacity, efforts should be made to ensure that health care decisions are based on the best interests of the patient and reflect, where possible, his or her own personal beliefs and values.

14 NYCRR Part 710

Procedures of the SDMC

Procedures of the Surrogate Decision-Making Committees of the New York State Justice Center for the Protection of People with Special Needs

Who Qualifies for SDMC?

Persons in need of a major medical treatment and are current or former service recipients of:

- Office for People with Developmental Disabilities (OPWDD)
- Office of Mental Health (OMH)
- Office of Alcoholism and Substance Abuse Services (OASAS)

Who Qualifies for SDMC? *Cont'd*

- Lacks the capacity to consent or refuse the medical procedure, and
- Has no legally authorized surrogate available and willing to provide consent

Major Medical Treatments Include:

Medical, surgical, dental or diagnostic interventions or procedures which involve:

- Treatments with a significant risk
- The use of anesthesia; i.e. IV, monitored or general
- Any significant invasion of bodily integrity requiring an incision or producing pain
- Any treatment/procedure for which informed consent is required
- Chemotherapy
- Hospice

MHL § 80.03 and 14 NYCRR § 710.3(j)

Major Medical Procedures Exclude:

- Routine medical care
- Psychotropic Medication
- Emergency treatment
- Dental care performed under a local anesthetic
- Electroconvulsive Therapy (ECT)
- Sterilization or termination of pregnancy
- Withdrawal of life sustaining treatment for non-qualifying individuals

MHL § 80.03

Who May Serve on a SDMC Panel?

Panel Includes Each of the Following

- NYS Licensed Health Care Professional
- NYS Licensed Attorney
- Advocate for Developmentally Disabled
- Family Member of Developmentally Disabled/
Former Patient served by SDMC/or another
Advocate

MHL § 80.05(c)(i) and 14 NYCRR § 710.3(m)



Withdrawal/Withholding of Life Sustaining Treatment

SDMC is authorized to make end of life care decisions for individuals with intellectual or development disabilities; including:

- Do Not Resuscitate (DNR)
- Do Not Intubate (DNI)
- CPR
- Withhold/Withdraw Artificial Nutrition and/or Hydration

SCPA § 1750-b and 14 NYCRR § 710.1(c)



The SDMC Declaration Includes:

1. Declaration for Surrogate Decision Making (SDMC Form 200)
2. Certification on Capacity (SDMC Form 210)
3. Certification of Medical Need (SDMC Form 220-A)
4. Supplemental Medical Information (SDMC Form 220-B)

The Declarant's Role

- May be any provider of health services, the director of the individual's residential facility, a relative, etc.
- Declarant is required to state that the patient has no available and willing parent, spouse, adult child, guardian, or other surrogate, and
- Must provide the factual basis for this statement and the efforts made to contact such persons

14 NYCRR § 710.4(b)

Lack of Ability to Consent to or Refuse Treatment

A person lacks the ability to consent to or refuse major medical treatment if he or she cannot:

- Understand the proposed medical treatment
- Understand the risks, benefits, and alternatives of the treatment
- Make an informed decision about the proposed treatment in a knowing and voluntary manner

MHL § 80.03(c)

Three Decisions Made by the Panel

1. Capacity

- Does this person have the capacity to understand the risks, benefits, and alternatives to this medical procedure?

2. Legally Authorized Surrogate

- Is there a legally authorized, willing, and available surrogate who can make this decision?

3. Best Interests

- Is this procedure in the best interests of this individual?

Informed Consent

Informed Consent Includes:

- Full explanation of the proposed procedure
- Description of the risks and benefits
- Level of discomfort and effect on functioning
- Disclosure of alternative procedures
- Must be a voluntary decision and the freedom to withdraw consent at any time

PHL § 2805-d

Legal Background- Case Law

- Union Pacific Railroad v. Botsford, 141 US 250 (1891)
- Schloendorff v. Society of NY Hospital, 211 NY 125 (1914)
- McCandless v. State, 3 AD 2d 600 (1957)
- Rivers v. Katz, 67 NY2d 485 (1986)

Capacity

Capacity Determination

- Adults with capacity may decide to accept or reject treatment
- Adults without capacity need a surrogate decision maker
- The SDMC determination of a lack of ability to consent applies only to the major medical treatment being proposed

MHL § 80.11

Three Elements of Capacity

Knowledge

Has the procedure or treatment been explained?

Intelligence

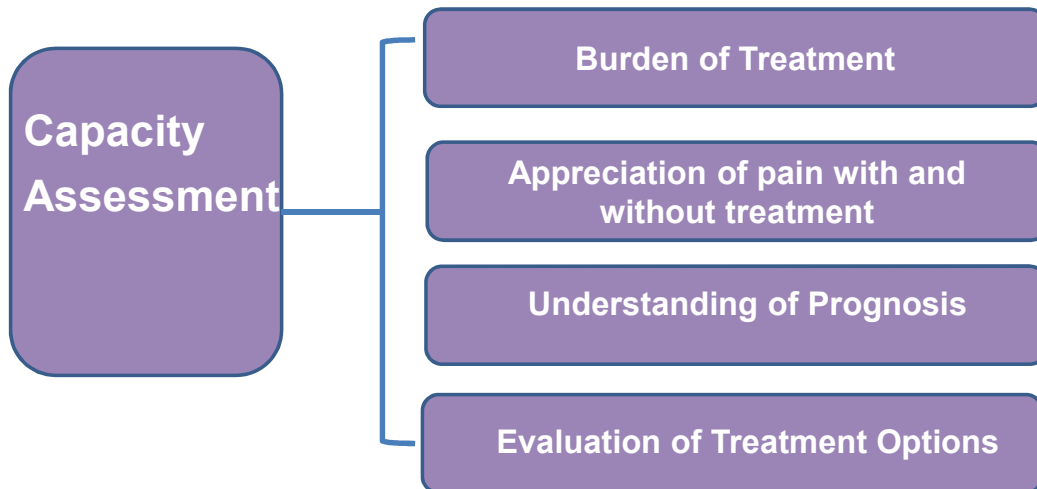
Can the individual demonstrate an understanding of the treatment?

Voluntariness

Decision must be made without outside influence

MHL § 80.03(c)

Evaluation of Capacity



Case Examples

- Extreme panic or anxiety affects decision-making
- Plain language explanation of procedure during the hearing
- Understanding of the risks and benefits of treatment vs. non-treatment

Legal Standard for Capacity

Evidence that is highly reliable and upon which reasonable persons may rely with confidence in the probability of its correctness

Clear and Convincing Standard

14 NYCRR § 710.5(c)(1)

**Legally
Authorized
Surrogate**

Legally Authorized Surrogates

OPWDD Programs

Hierarchy defined by regulation:

1. Lawfully empowered Guardian/ Health Care Proxy
2. Actively Involved Spouse
3. Actively Involved Parent
4. Actively Involved Adult Child
5. Actively Involved Adult Sibling
6. Actively Involved Adult Family Member
7. A Surrogate Decision Making Committee or a Consumer Advisory Board for Willowbrook Class Individuals

14 NYCRR § 633.11

OMH and OASAS Criteria

- Spouse
- Parent
- Adult Child
- Court of Competent Jurisdiction

14 NYCRR § 27.9

Legally Authorized SDMC Surrogates

Receive a Waiver Letter from SDMC

- Health Care Proxy
- Legal guardian/Court appointed guardian
- Parent
- Spouse
- Adult child or family member

14 NYCRR § 710.5(a)(3)



Correspondent

- A person with a genuine interest in promoting the individual's best interests
- Personal relationship with the person, participating in their care and treatment
- Regularly visiting or communicating with the person

Correspondents have the right to:

- Notice of hearing, to participate in the hearing and to appeal any decision of the panel

MHL § 80.03(k) and 14 NYCRR § 710.2(d)



Health Care Proxy (HCP)

- The agent is the preferred surrogate
- Execution of the HCP must meet special criteria in order to be valid per OPWDD regulations
- No need for SDMC if HCP was executed properly and the individual is determined to lack capacity

14 NYCRR § 633.20

Guardianship Considerations

- A guardian may or may not have legal authority to provide medical consent
- If the guardian dies or becomes incapacitated, SDMC may act on behalf of the individual

Legal Standard for Surrogacy

Evidence that is highly reliable and upon which reasonable persons may rely with confidence in the probability of its correctness

Clear and Convincing Standard

MHL § 80.07(f) and 14 NYCRR § 710.5(c)(1)

Best Interests

Best Interests

Promoting personal well-being by the assessment of the risks, benefits, and alternatives of a proposed major medical treatment by taking into account:

- Relief of suffering
- Preservation or restoration of functioning
- Improved quality of life
- Individual's quality of life with and without treatment
- Personal beliefs and values held by the individual

MHL § 80.07(c),(f)

Best Interests Regulatory Standards

- Burden of Treatment
- Level of Pain
- Prognosis
- Treatment Alternatives

To the extent possible, the panel gives full consideration to any known or stated preferences from the individual

14 NYCRR § 710.4(d)(1) & (3)

Legal Standard for Best Interests:

Evidence that when weighed for its quality, rather than quantity, tips the scale to give consent or withhold consent for the proposed procedure/treatment

Fair Preponderance of the Evidence

MHL § 80.07(c) and 14 NYCRR § 710.5(f)

SDMC Case Review and Hearing Process

Notice of Hearing

The surrogate and all interested parties receive a five-day notice of hearing

The SDMC hearing may proceed if

- ✓ Surrogate waives his/her right to make the decision
- OR
- ✓ Fails to respond to the notice of the hearing

Expedited cases may waive the five day notice requirement

MHL § 80.07(b) and 14 NYCRR § 710.5(a)(4)

Prepare for the Hearing

- ✓ Ensure you have no conflicts
- ✓ Do not discuss or seek opinions of others
- ✓ Do not research or call the physician
- ✓ Formulate questions for hearing
- ✓ Contact the SDMC Nurse if you have questions
- ✓ Avoid ex-parte communication

Hearing Participants

- Declarant, Nurse, Providers
- Patient
- Four Panel Members
- Mental Hygiene Legal Service (MHLS)
- Local SDMC Coordinator
- Any correspondents and interested parties to whom notice was sent

The Hearing

Quasi-judicial Process - formal rules of evidence do not apply

- Similar to court proceedings: evidence and testimony
- Hearsay is allowed
- Impartiality
- Due process: adequate notice of the hearing
- SDMC provides legal assistance and support to the panel

MHL § 80.07(d) and 14 NYCRR § 710.5(b)(6)

Chairperson Responsibilities

- Opens and closes the hearing
- Maintains order and professionalism
- Closes one issue before moving on to the next
- Redirects others during the hearing when necessary
- Panel Members may ask questions, but may not provide testimony or bring research to the hearing



Mock Hearing

Surrogate Decision Making Committee (SDMC)

The Hearing Record

- SDMC Records are maintained ten years
- Hearings are recorded; attendance record; testimonial and documentary evidence
- Testimony on:
 1. Capacity
 2. Surrogacy
 3. Best Interest
- Deliberation and voting are off the record
- Closing statement and panel decision

Hearing Issues

Hearing Issues and Possible Options

- **High risk procedure**
 - Contact MD/Health Care Provider or the SDMC Nurse for more information
 - Request a second medical opinion if necessary
- **Avoid treatment planning and providing testimony**
 - The panel may consider the treatment plan in the declaration and what alternatives considered
 - Although panel members have professional knowledge, they may not “testify”
- **What if the individual voices opposition to the procedure?**
 - Consider the capacity standard
- **Weak testimony**
 - Consider documentary and testimonial evidence

Treatment Planning, Testimony & Bias

- Be careful of crossing into treatment planning
 - You **may** ask about alternative procedures
- Ask the question
 - Avoid testifying during the hearing
- Be aware of your own bias regarding procedures

Deliberation and Voting Procedures

Deliberation and Voting

- Only the four panel members participate
- Recording of the hearing is paused
- Objections by MHLS may be considered
- Capacity, surrogacy, and then best interest vote
- Panel members may share their own knowledge and opinions at this time
- Hearing may be reopened for additional testimony and information

Three Votes

“The Rule of Three”

- Three votes that the individual does not have capacity
- Three votes that the individual does not have a willing and available surrogate
- Three votes that the procedure is in the individual’s best interest

Possible Hearing Outcomes

- Consent is issued
- Consent is denied
- No decision (2-2 vote)
- Person has capacity to make the decision
- Person lacks capacity, but does have a surrogate
- Conference Call - When additional information is needed to make a decision

SDMC Consent

- Typically valid for 60 days
- Not issued to a specific health care provider
- Additional consents are not required
- Not specific to the type of anesthesia
- Contain a clause allowing a physician to move forward with related procedures

Post-Hearing Conference Calls

- Same panel members from the original hearing participate
- Case information will be sent by mail, fax, or encrypted email
- Phone number and conference code will be sent with the case information

14 NYCRR § 710.5(b)(4)(iv)

Objections, Denials and Appeals

Objections

Any interested party may object, including MHLS, potential surrogates, correspondents, or other interested parties

Only an objection from a legally authorized surrogate stops the SDMC proceedings

MHL § 80.07(g) and 14 NYCRR § 710.5(b)(7)

MHLS Objection

- Does not stop the hearing
- Objection is noted on the record with due consideration during panel deliberations; objection to notice of hearing is different

Exception:

MHLS Notice Objection

Right to Appeal

- Patient
- Declarant
- Authorized Surrogate
- MHLS
- Correspondents
- Director of the patient's residential facility

MHL § 80.09 and 14 NYCRR § 710.6(a)

Appeal Process

- Appeal to Supreme Court, pursuant to Article 78 of the CPLR
- Is the determination by the panel supported by substantial evidence?
- If a trial is required, it shall receive an immediate preference, as provided for in CPLR section 3403
- TRO may be granted

MHL § 80.09 and 14 NYCRR § 710.6(a)

Confidentiality

HIV Information and Confidentiality

HIV related health information has additional protections and penalties for unauthorized disclosure

- HIV related information will be redacted from the case if not pertinent to the case

PHL Article 27-F

Health Insurance Portability & Accountability Act (HIPAA) and SDMC

- Established national standards for the protection of certain health information
- All private health information must be properly protected
- Includes all identifying and clinical information, including the fact that an individual is receiving services
- Panel may request and receive and information relevant to proposed treatment or need for SDMC

MHL § 80.07(c)(1)

SDMC and Confidentiality

- Encrypted email
- USPS mail or Fed Ex
- All copies of PHI are returned to the SDMC Coordinator at the hearing, or permanently deleted electronically
- Redactions may be noted in the documents

MHL § 80.07 (c)(1) and MHL § 33.13

Public Officers Law § 74 & Oath of Office

Public Officers and Indemnification

As public officers, carrying out the duties of the NYS Justice Center's SDMC program, panel members would be indemnified and defended by the Attorney General

Roles & Responsibilities of Panel Members

- Impartial decision maker
- Maintain standards that promote fairness
- Integrity and independence in decision-making
- Decision-making considerations are for the individual's best interests

Public Officers May Not:

- Accept other employment which will impair independence of judgment
- Disclose confidential information
- Use their official position to secure unwarranted privileges or exemptions
- Engage in ex parte communication

Public Officers Law § 74 Code of Ethics

Conflicts of Interest

- Relative of the individual at the hearing - or another panel member
- Affiliation with the residential facility or potential financial benefit
- Employee, officer, or board member of a licensed provider
- Strong bias against procedures, treatments, or specific diagnostic tests

14 NYCRR § 710.3(c)

Next Steps for Volunteers

- If you would like to become a volunteer, please sign the Oath of Office and complete the Panel Information Sheet
- You will receive an Appointment Letter from the Justice Center
- Your regional coordinator will be in contact
- Consider future trainings to serve as a Panel Chair or on an EOL Panel



Contact Information

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