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Gleason

By Clay Tweel

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All right, let's talk a little
bit more about you.

You-- Right there.

That's where you're gonna be in,
like, six weeks.

Um...

My number-one focus of purpose
is to share with you who I am
and to...

give you, uh,
as much of myself
as I possibly can
while I can.

And I'm excited.

I'm excited.

I want you to come
sooner than later
so I can still hold you--
Hold you and--

You in my hands and my arms.

and use all that stuff--

Just--

Just love you.

The 6th of October, 2001.

We're heading down to the
OSU-Washington State game
where the game is sold out.

MAN:

Homecoming.

Another beautiful day in...

Spokane, Washington.

[CHUCKLES]

Oh, it's a great day.

Cougs are favored by 10.

Steve doesn't like it.

I like it.

Oh, man, it's a beautiful time.

It's a beautiful time
for the Cougs.

MAN 1:

Steve Gleason has what every

college football coach
is looking for in a linebacker.

MAN 2:

Really, really fast.
Really, really aggressive.

MAN 3:

He may be small
but no one can deny
Steve Gleason's ability to hit.
I think that playing football,
you know, is a great time for
every guy to get out there,
you know, and let out your
aggression
and just kind of be
a free spirit.
Cougar football at its best.
Gleason and me. Two legends.
He pass blocks,
you take a step back.
He run blocks,
bam, you're in there.
For the average college
linebacker, he was too small.
And he was way too small
for the NFL to play linebacker.
He had to work harder,
run harder,
train harder,
just so he could be the guy
that was gonna be on
that 53-man roster.
I'd never seen a guy
cover kicks the way he does.
It takes a certain type of
psyche and mindset to do that.
It's actually kind of a crazy,
sort of loose cannon,
"this guy's obviously got
a few screws loose"
type of mindset.
And that's what made him

so good.

I consider Steve a real Kamikaze
of sorts, you know,
notorious for sticking
his head in there,
totally giving up his body,
tough.

Male reporter:

There are reports
from New Orleans
of people trapped
in buildings
that have come down
around them.

The Superdome became a symbol
of failure and despair.
20,000 refugees lived here
for one miserable week
without power, water,
or sanitation.

[CROWD CHEERING]

Female reporter:

A beautiful day,
and an unbelievable scene
here inside
the Louisiana Superdome.

[MEN SHOUTING, CHANTING]

Who are we?

Saints!

Are we ready?

[BARKING]

New Orleans!

[BARKING]

[CROWD CHEERING]

Man:

A moment almost unimaginable
13 months ago is here.

Look out! Right through!

A pickoff by Steve Gleason!

And score!

Touchdown! New Orleans!

And for those people who look
to the New Orleans Saints
as something that will
uplift them, uplift this city,
uplift the entire Gulf Region,
they've just had it!
That night, and specifically
Steve blocking the punt,
was, like, a signal
to everybody that not only
is New Orleans back,
but it just felt like
the rebirth of something
really, really big.

[LAUGHS]

Can you effing believe that?

All right, we need
another performance.

Oh, gee!

Back to back

with the Rio Grande

A Christian woman

in the devil's land

She learned the language

and she learned to fight

But she never learned how

to beat the lonely nights

In Lonesome Dove

Lonesome dove

STEVE:

I want to teach you
how to hold the camera.

Okay.

Yeah?

How's that?

Fine.

Are you there?

I'm here.

You don't like to talk
behind the camera?

I'm a filmer,

I'm not a subject.

Yeah, but a good filmer

asks really good questions
to get really good material.
Are you almost done?
Good question.
When I first got to know him,
he plays--
He had long hair
and played for the NFL.
I thought he was gonna be
a complete cheeseball.
But when I met him,
he was perfect.
I thought he was the greatest
thing I've ever met.
He lived in a small house
and didn't have a TV
and drove a truck and was
different than Southern boys,
and he loved to, like,
adventure travel.
I liked to travel
at the time too.
He was this superhero athlete
but also super smart.
He was the best of both worlds,
let's say.
With the kind of person
that Steve is,
he was attracted to
the free spirit of Michel.
the kind of honest bluntness,
uh, willing to try anything,
really no airs about her.
[CROWD CHEERING]
I don't know, you can never
think of Michel settling down.
She was always the life
of the party.
She was always having fun.
Is Michel really
gonna settle down?
Is Michel gonna have kids?
No way.
That's not gonna happen.

STEVE:

No, you gotta try again.
Watch your hams.
As unique as Steve is,
Michel is equally as unique,
and I think she was still
trying to find herself
and didn't know
where she was going.
And I think when she met Steve,
they just started clicking.
And I think it's such
an amazing thing
that both of you said
to me yesterday.
Even if it's pouring rain,
it doesn't matter.
We have each other.
Our family and friends
are gonna be here.
And isn't that, really?
As all us married people know,
it's how we act,
not when things are great--
It's easy to be loving to each
other when things are great.
But how do we act
as a couple together
when things aren't great?
When things are difficult?
[CHEERING]
Bye!
Now I guess we could say
you're officially
a New Orleanean.
You married a local girl, you
live in a historic neighborhood.
Are you a New Orleanean?
It's a city that I love.
I'm very thankful for all that
has come to me through
this city.
Is it okay with you,

the fact that you're kind of
synonymous for one play?
You played nine years
in the NFL.
You were on the Saints team that
won the first-ever playoff game.
Look, if you gotta pick one
thing that you're gonna
be known for,
that is fine with me.
And before we go,
I wanted Steve to wear
his Number 37 jersey
for this segment.
But he won't put it on.
I wear my jersey on the field.
Those days are done.
So I've been having
some strange medical issues
going on with me recently.
I've been having some
muscle twitching in my arms.
Mostly my upper arms,
shoulders on both sides.
And some in my chest,
in my back,
a little bit in my upper legs.
I then also talked
to my naturopath,
and he seemed a little bit
concerned about it.
He spoke about these types
of symptoms on three levels.
It could be some type
of molecular problem,
or it could be some type
mechanical problem,
meaning my neck or my head
have some type of trauma.
I have a bulging disc
or a ruptured disc
or calcification
in my vertebrae
from all my football trauma.

Thirdly, it could be some type of neurological disease, a disease that he mentioned as--

Obviously the worst-case scenario would be ALS, which is Lou Gehrig's disease. I have been diagnosed with amyotrophic lateral sclerosis, which is a disease in the motor neurons. And this disease is--

Is almost always fatal. My first reaction was kind of frustration or anger at the doctor for saying it. And I just was like, there's no-- There's no way. He's telling me this, but I don't necessarily believe what he's saying. Although this is part of the challenge, like, yeah, I wanna beat ALS, I want to win that part of the game, But for me, the biggest part of the game is beating all the other shit that you and I have talked about is karma from our parents or relationships with family or relationships with friends or your own spirituality and just peace in your heart. But I just think there's a bigger battle there about being able to say, "Okay, I have been-- I have this diagnosis, and it's not gonna-- It's not gonna crush my life, even if it does crush,

you know, crush my body."
I think you look
really cute today.
I haven't smelled you,
but you look really cute.

STEVE:

I wish I could
zoom in on that.
Damn.
Is it hard not to tell?
I know it's a boy.

STEVE:

[CHUCKLES]
But I know more.
Yeah... right.
Before this,
we wanted a baby,
and after this,
just because it meant that
I'd have to help
take care of him.
It wasn't a big enough reason
not to have a baby with him
and have all the beautiful
things that having a baby,
you know, bring to a family
and a couple.
Here you go, Steve-O.
It's definitely in there.
What is this all about?
I am making a video blog
of myself.
This is intended to be
a gift for you,
my child
who I have not yet met.

MICHEL:

Do you think it already has
a hard head?

WOMAN:

That comes from his dad's side.
My intention is to pass on
as much of who I am
as possibly can to you.
And I think if I can do that
in a good way,
it can be even more meaningful
than having
a father who's around
for 30 or 50 or 60 years
of your life.
Now, I hope that happens too,
but this is a nice little
backup insurance plan.
For me, the weird thing is--
The scary thing is, like,
every week or so
there's a new thing
where I'm like,
"Oh, I can't do that."
I'm losing that.
I lost that, just lost that."
[MAN SHOUTING]
We have to have
a pregnant woman to start us.
Is there any pregnant women
in the house?
We got one pregnant woman!
Well, get in, girl,
you're the starter.
On your marks.

MAN:

Get set.
We're set!
Go! Go, go, go.
Not everybody knew
that Steve had ALS.
They were treating him
like was still a healthy
ex-football player.
I hadn't cried, I think,
in a long time.
It's just kind of like,

this is gonna be okay.
But seeing that kind of,
like, awkward gait,
it crushed me.

[PEOPLE SHOUTING]

Yeah, buddy!

You did it!

Stretch! Stretch.

Stretch.

[SPEAKING INDISTINCTLY]

Good job, dude.

No one knows what

I'm feeling right now.

I don't want want him

to go through this.

I don't want to deal with this.

For the first time,

you don't want to realize

that this is the truth.

And in those moments

you realize it's the truth,

and, like, this is fucking

happening to my husband.

This is happening.

STEVE:

I think the big question is,

"Why is this happening?"

You know, me and Michel

are so good together.

We're so perfect,

being really good people.

So I kept asking

over and over again,

"God, if you have some

control over this universe,

"why would this happen to me?

"If you have control over this,

"then save me, you know.

Help heal me.

Because I don't want Michel

to be here by herself."

[OVERLAPPING CHATTER]

I'm sure there are people

that get this diagnosis
and just kind of shut down,
whereas it's kind of ignited
a fire in me
where I'm not gonna shut down.
Not only am I not
gonna shut down,
I'm gonna go a little bit
further, you know?
Push the envelope a little bit.

[WHOOPING]

Yes, I understand
That every life must end
Uh, huh

MICHEL:

Hell, yeah!
Halleluiaah!

MICHEL:

Uh, huh
Oh, I'm a lucky man
To count on both hands
The ones I love
Some folks just have one
You know, I was torn.
A lot of people were saying
I shouldn't necessarily
go on this trip.
I should be seeking out ways
that I can get healed
or get some treatment.
In the end,
I think I decided that
the odds of me finding
some type of treatment
in the next six months
were too small.
It's gotten a lot harder
for me to do stuff.
The other thing that's really
frustrating for me
is the talking.
So it's getting harder

for me to talk.
I know I've said this
before on film,
but it's not gonna stop,
I guess.
It's probable
that it won't stop.
Hold me till I die
Meet you on the other side
Quite possibly one of the
coolest things I've ever done.
We've been, what,
around the world,
and in front of millions
of people,
but that plane flight
was amazing.

MICHEL:

Glacier landing
versus punt block.
I don't know, it's close.

MICHEL:

Want to tell the baby anything?
We had a destination in mind
when we came up here,
and I would say we are there.
Be present now, right?
Better late than never.
Better now than never.
Better now than never.

MAN 1:

MAN 2:

Sorry.
My favorite part is
to do things like this.
Hello. Hello.
Hey, how are you?
Oh, how are you now?
Well, things changed since
you're here to now.

Nothing has changed for me.
It's a couple seconds.
For you, though? Huh?
Things have changed.
Like, it's weird
that I'm potentially having
a conversation,
initiating a conversation,
with someone who I actually
might never talk to
in a real conversation.
Mm-hmm.
The baby will be born
in November.
So I'll talk to it, sure.
But let's say a real
conversation starts
at 4 years old.
Maybe I'm not having
conversations at that point.
It's fucked up.
So then it's like,
well, if I was that person...
what would I want
to hear people say?
What would I want to hear
my dad say?
You know?
You just want him to be real.
Yeah, so that's why I'm like,
"Look this is just raw and...
unprepared--
I mean, the same shit
we want when our dads are alive.
We dislike what
so many parents do
is like, "I'm parent now.
"I'm not a person anymore.
"I'm not real.
Yeah.
"I don't have all the exact
same flaws as you.
...doing the exact same stupid
shit that you're doing."

The big thing that's happened since I've been diagnosed in January is that one thing I want to accomplish is to have all my relationships in order is the term I've been using. In my teenage years, my dad was very protective. His only way to teach how to live life was to teach it out of fear.

STEVE:

As much as possible, try not twist like that. You got all your questions there? Yeah.

That's good.

So I think a good place to start, Dad, would be-- How about your birth?

Yeah, the very first memory of me as a very young child.

What were some of the things that you remember?

Is that thing on?

Yeah.

It can hear what you just asked me?

Yeah.

Okay.

He was a reader, pretty cerebral.

He wasn't an introvert, but he was more on the quiet side,

I can remember he was about 6 years old,

and I had him in the backyard.

He was at the farthest end of the lot in the backyard.

I bought him a Wiffle ball
and a bat.
I said,
"Keep your eye on the ball,
and watch the ball hit
the bat."
So I tossed it to him.
First time he swung the bat.
He hit the ball over the house.
And we're talking
plastic Wiffle ball.
And I thought, "Holy crap.
What do I have here?
Our parents got divorced
when I was 15,
and you were 11 maybe?
Something like that.
And so growing up,
what I remember
is that they would fight
all the time.
A lot of verbal abuse.
Our parents literally
screamed at each other
for hours, just like screaming
as loud as they could
for hours and hours and hours.
There reached a point between
Mike and I where things got
pretty bad
and the boys
did not like that,
especially when I started
going to therapy
and learning how to stand up
for myself again.
Then that got pretty tense.
I didn't have experience
in how to raise somebody.
My father was never home
when I grew up.
So I didn't really have
an example of how a father
should be.

So I was just doing
the best I could do.
I probably over pushed
in some areas
just because I just saw
a lot of talent there
and somebody that had
fierce determination.
So I thought, well,
there's a lot
this kid can do.
And here come the Cougars!

MAN:

There's Stephen right there.
When you saw--
How the interaction was
as a family--
And things weren't right
between your mom and I--
That you can take all that
frustration out on the field.
And it was a great way
for you to release
pain, anger, uh...
And I hate to say it,
but that was
one of my motivations
when I played ball.
'Cause my own life
with my parents
was pretty dysfunctional.
And you grew up in a pretty
dysfunctional marriage.

STEVE:

The biggest thing my dad
has contributed to me
is just determination,
perseverance. Hard work.
I mean, the guy
to a fault, he works hard.
I ended up in a 12-step
recovery program

for workaholism and anxiety.
This a biblical principal
and it's in the Old Testament,
but it says,
when the kings
and their sons would sin,
the generational sin
would go from one family
to the next
unless somebody in the family
would get before the Lord
and say,
"Okay, God,
forgive me for this."
I'm not doing this anymore."
Somebody has to stop the sin
or else that sin runs
from one family to the next.
Okay, a topic based blog here.
Today's topic will be religion.
God. I don't believe God
is a father figure
white-haired man up in heaven.
I don't believe in the fear
that is in the bible.
The fear tactics
that are used in the bible.
I believe in love.
Treating someone else
as you would like to be treated
is my number-one...
rule.
The more I pray,
and the more I read
about this stuff,
the more I believe
God wants me here.
Now, wait a minute,
if that doesn't happen,
I can accept that.
Okay.
The more I hear you saying,
God wants to heal you.
God wants to heal you,

and I'm like, hmm,
that's interesting because
it says in the bible
that we don't know God's mind.
No, that's not true.
It does say that though.
So are you saying
that since I'm--
I'm not saying--
Since I'm sick
and if I die it's because
I don't have the mind of Christ?
I'm not saying that at all.
I would never say that.
Never.

I'm feeling open
and a little bit
anxious and nervous.
How are you feeling?

About the same.

About the same.

Let's give Kevin a warm welcome.

[CHEERING, APPLAUSE]

It's a privilege
to be back here again.
I think we were here
about three years ago,
wasn't it?

Four years?

Three or four years ago.

When I started reading
that book,

I started feeling
inside of me
that I should lay hands
on my own son,
but I was scared,
just like he was,
because I didn't want it
to not work.

Well, just do it.

[WHISPERING INDISTINCTLY]

We're gonna get there.

This whole thing's

gonna be easier, Michel.
It's gonna take time.

KEVIN:

We're gonna focus
on ourselves right now,
and we're gonna put our hand
on our body parts.
Later, we'll put our hands
on other people.
Later on.
But we'll start here first.
And then I want us to sing
"It's The End of My Pain
As I Know It."
Are you ready?
Let's do it, Kevin.
It's the end of my pain
as I know it
It's the end of my pain
as I know it
It's the end of my pain
as I know it
And I feel fine

KEVIN:

Okay, now, check your body out.
Try to make it heard.
Try to do something
that you couldn't do before.
I'm gonna go run.
See if there's 10 percent,
20 percent, 30 percent
difference,
50 percent,
100 percent improvement,
some kind of improvement.
Come on, try to make it heard
real quick.
Now, wave your hand if you had
some kind of improvement.
Right there. Right here.
Right there. Right over here.
Right back there. Right here.

I'm gonna run.
Okay, go for it. Right here.
I'm gonna run.
Right here. Right there.
Should I run?
Wow! Look at this.
This is awesome.
This is awesome.
Just go do it.
This is-- Go. Just go ahead.
Just check it out.
Try to make it heard right now.
Okay, wave your hand if you've
got some more breakthrough.
Look at this. More.
Okay. All right. Good try.
Here let me have your hand.
Good try.
Try again.
Yeah, that was how many steps?
Four steps.
[APPLAUSE]
Let's get a couple big guys here
as well
and come alongside of him
to run with him.
You're a big guy.
Come on.
You in the blue.
There you go.
Don't touch me.
This is bullshit.
It's not bullshit.
Yes, it is.
So at this point,
what we're gonna do is
these guys are gonna go back
there and practice this
while I continue.
There you go.
Keep up with him.
He's gonna tell you it will
happen when he leaves you.
He said usually things happen

once he's gone.
Just so you know.

MIKE:

Michel, you're his partner.
You need to trust
and believe with him.
You really need to--
She's with me all the way.
I am with him so much,
Mike.
I know you are.
Don't you dare say that to me.
It's okay.
Michel, come on in.
Everybody's different.

WOMAN:

I know. That's what
she just said, though.
I feel sick.
Okay.
The team's gonna come this way
and go past us that way.
Okay.

MAN:

It was a surprise appearance
by Steve Gleason.
His first appearance on camera
since going public
that he had been diagnosed
with ALS.
Obviously, I don't
how to move or talk
quite the way I used to.
When you're good at something,
it's fun to see other people
admire you.
And I think that's a good thing
to be so good at something
that people admire you.
But I think it could be
dangerous if that becomes

obsessive.

And I certainly struggled
with that when I retired.
If you're not doing something
where there's tens of thousands
or millions of people that are
admiring you,
can you still be happy?

Tough question.

It was just prior
to the Saints home game
on September 25th
with the Texans
that Gleason went public
that he had been diagnosed
with ALS.

He was named an honorary captain
for that football game.
and came out at mid-field
to lead a "Who-Dat" chant
that no one will ever forget,
especially Gleason.

STEVE:

When I would play football,
during games, I would have
this fear of walking
onto the football field.
And I would tell myself,
"Hey, if I die today
"or on this play,
then I'm okay.
"I've had a good life,
and I feel good about
kind of accepting death."
At the same time,
I think that
that thought and maybe
the actions that followed it,
sometimes I think that's--
That might be why
I have ended up
where I am right now.
And now I think about it,

and I don't want to die.
[CROWD CHEERING]
[CROWD CHANTING]
WHO-DAT?! WHO-DAT?!
WHO-DAT?! WHO-DAT?!
WHO-DAT SAY
DE GONNA BEAT DEM SAINTS?!

MAN:

So for now,
Gleason's goals are clear.
Live each day to the fullest
and spread the word about ALS.
If I could help show
and inspire people to--
That have been diagnosed
with ALS to continue living
their life,
and if we can,
as a group,
uh, if we could help
those people--
Those people who have been
diagnosed continue to live
a life that's enriching
and extraordinary,
um, then I think, uh,
that's part of my goal.

MAN:

We have to define your purpose.
To me, there's two things
you can do
in terms of medical disease
related fundraising.
Either for research for a cure,
or for services, equipment,
technology, etc.
I chose services and equipment
as opposed to research.
Okay.
I want to accomplish two things.
I want to advance those
technologies, services,

and equipment.
And I'd like to provide people
with purpose.
We had a kid who e-mailed me.
He said,
"I'm 29, I just read your entire
blog about going to Alaska.
"That's been a dream
of mine forever.
I got diagnosed with ALS
two months ago."
My idea is to create ways
for ALS patients,
even if they can't move, to
participate in these projects,
these expeditions.
But that's-- If all goes my way,
that's what I'd like to do
with the money
that we raise
for this foundation.
[CRICKETS CHIRPING]
MAN [OVER SPEAKER]:
Legally, for the formation...
No, no, no.
We do need something
for the foundation.
Yeah, for, so, Jim--
[JIM CONTINUES, INDISTINCTLY]
Thank you so much, guys.
Have a great night.

MAN 1:

MAN 2:

MAN 3:

Late.
That was sweet.
[WATER RUNNING]
Hi.
[MICHEL SPITS]
Good morning.
Hi.

Hey you. I'm sorry.

MICHEL:

That's okay.

STEVE:

I don't know why I did that.

MICHEL:

I don't know either.

STEVE:

You are so important.

You know that.

You are, you're it.

You're, you're it.

You're it.

All that other shit

doesn't matter.

MICHEL:

Okay.

I'm telling you,

I'm serious.

But I am kind of excited

because I think

we could create something here.

Buddy,

I think it's great.

I mean,

I think it's great.

We have a passion,

a project,

something that we have to

live for.

Steve, this is--

That's raw, you know.

This is--

Look, this is--

That is nothing

why I'm crying,

this has nothing

to do with that.

I don't know

why I'm crying.
I want you
to help me create it.
I know. Steve,
I'm here with you in every step.
It's not like I'm not--
I know. I'm just saying
I want you to feel like
we need you to create this.
This is...
There's things that you can get
too involved in,
but I think that this is
great stuff.
The contractions,
I can't even tell,
'cause there's so much pressure
all the time,
and they've moved from
my hernia down to my--
It's go time.
It's go time.

JULIE:

Michel, that is how labor is.
It's not back labor.
Do you have any fluids coming
out at all?
I just had
a tiny little thing
of pink this morning.
Okay. You're in labor!
Julie,
but we don't know yet,
so I don't want to be
one of those people--
Yeah, I know. Okay?
Sarah's sitting right here
and she's like
"She's having a baby."
You're having the baby today.
Steve, are you ready?
No choice.
[JULIE LAUGHING]

No choice.
I'm letting you know
in advance,
it's going to be
very difficult for me,
pushing this thing
out of that little hole.
You're gonna do great.
I'm gonna help you.
There's things in life that
are hard, but you just gotta do.
I know, but do you understand
what's about to happen?
If it happens.

WOMAN:

Michel Varisco.
Well, it's, uh,
October 19, 2011.
We've done several of
these types of journals,
but, uh, it's, uh--
It's go time.
I've been scared about
doing this for my whole life.
[HEART MONITOR]
Come on out,
little buddy.
Come on out.
Oh, sweet Jesus, Steve.
I want a kiss.
You got it.
Michel, I love you so much.
I love you.
And we're doing the--
Really, the coolest thing
we could do together, right?
That's right.
Fuckin' right, dude.

MICHEL:

Dun-da-da-dah!

DOCTOR:

Let's see.

All right, this is it, guys.

There you go.

[INDISTINCT DIALOG]

DOCTOR:

We're gonna do

most of the work.

Give me a deep breath.

Give me a little half push.

There we go.

All right, no more.

Let's go straight up,

Steve. Ready?

Straight up.

Hold right here.

Ready? Watch this.

MICHEL:

He's little. Look at him, Steve.

DOCTOR:

Okay, Michel, look at your baby.

Look at this baby.

Look at that beautiful baby.

All right, Steve,

get your hand here.

We got it, it's okay.

There it is.

We got it.

You got it, I don't have it.

You got it.

You got a baby boy.

[LAUGHING]

You got a baby boy.

Wait, can you hold him?

I got him.

MICHEL:

WOMAN:

That's my boy.

[INDISTINCT CHATTER]

I don't know

how to hold him.
I don't--
I don't think that's mine.
You don't?
I mean,
it doesn't even seem real.
[BABY FUSSING]
It was so easy.

WOMAN:

You did it good.
You were great.

STEVE:

Mick, you did great, dude.
I'm ready for number two.
[LAUGHING]

STEVE:

Well, okay.

STEVE:

Rivers and roads

MICHEL:

Rivers and roads

STEVE:

Rivers and roads
That's, uh,
Rivers Varisco Gleason,
your grandson.
Rivers. That's what you
named him, Rivers?
Yep.
What's his middle name?
Varisco.
Oh. Just like her last name.
[LAUGHING]
Rivers Varisco Gleason.
Rivers.
[LAUGHING]
All right.
[LAUGHING]

So are you at
the hospital?
Oh, yeah, dude.
Dad, we had the baby,
like, half an hour ago.
Half an hour ago.
Yeah, man.
What's up, Rivers?
You're right here.
Uh, all right.
October 20, 2011,
and this will be...
[CLEARS THROAT]
...my first video journal
where we're in it together.
How about that?
It's also the first
video journal where
I get to...
talk to you in, what,
the first person
rather than using pronouns.
Uh, I'm scared.
We don't know
what the hell we're doing.
Anyhow, the big thing is,
I'm writing a bunch about
what the word and the name,
and-- And what rivers
actually mean to me.
I came up with this
several years ago,
but I decided that rivers
are the source of fire.
Here's my logic.
A fire burns wood
as its fuel,
and this wood
comes from a tree
that drinks from the rivers,
and so, uh, the rivers
are the fuel for the fire.
And, uh,
you are the rivers...

for my fire.

[Van Morrison's

"Crazy Love" playing]

I can hear

her heart beat

For a thousand miles

And the heavens open

Every time she smiles

And when I come to her

That's where I belong

Yet I'm running to her

Like a river's song

She give me love,

love, love, love

Crazy love

She give me love,

love, love, love

Crazy love

She give me love,

love, love, love

Crazy love

She give me love,

love, love, love

Crazy love

She give me love,

love, love, love

She give me crazy

She drives me

a little crazy

[INDISTINCT DIALOG]

[CHEERING]

Today I'm gonna

talk about, uh...

um, my insecurities.

I think I cared a lot about

what people thought of me,

and, uh, suppose I--

I battle that even today.

Um, ahem,

I wonder sometimes

if I'm doing too much

because people

want me to do a lot.

You know, people are like,

oh, you're a hero, you're--
uh, ahem, you're, uh--
[COUGHS]
you're an inspiration,
so I'm, like, okay,
what can I keep doing to
continue to be an inspiration?

[PHONE RINGS]
Hello.

WOMAN:

This is she.
Hi, Michel, it's Melanie,
and I am here
with Jim Eutizzi,
and then, um, a couple people
that I work with.

MICHEL:

Oh, okay.
How are y'all doin' today?
Good.
I'm here with my husband Steve,
and our baby Rivers.
And we've got a, uh--
A message to give Jim.
[BABY BABBLING]
That was from Rivers.
That was hello
from Rivers.
And from us, uh,
we wanted to let Jim know,
well, ask him if
he'd like to, uh--
To go to Italy with his son,
because we've already
bought him tickets
for about 12 days in June.
Here are your tickets.
[SOBBING]
Okay, Michel.
Well, does he
want to go or not?

MELANIE:

You want to go, right?

Oh, God.

I don't know what to say.

That is so awesome,

Melanie.

[INDISTINCT DIALOG]

I don't know what to say.

Hi, this is Kurt Warner,
and I support Team Gleason.

No white flags, baby.

Hi, I'm John Elway
for Team Gleason.

No white flags.

I'm Reverend Jesse Jackson.

I support Team Gleason.

No white flags.

I'm Mike McCready,
badass guitarist for
the greatest rock band ever,
Pearl Jam.

Hey, I'm--

I'm Steve Gleason.

I'm a totally incredible
human being

doing fantastic work
with Team Gleason.

Always remember.

Always remember,

BOTH:

no white flags.

[NO AUDIBLE DIALOG]

STEVE:

It's my belief that
most of what ALS takes away
from people,

technology can give back.

It transpires that

my oeuvre has evidentiary,
not literary, merit.

Damn it.

MICHEL:

You lose your voice
when you have ALS.
And so he found--
He researched this place
where you can actually,
um, voice bank,
so his mechanical voice,
instead of being like
Stephen Hawking,
his is gonna be his voice.
Senator Russ Feingold
of Wisconsin
also took himself
out of the running.

[]

Then it goes to
eye technology
where he talks with his eyes,
but he's talking
a letter at a time.

WOMAN:

When you see
the green dots in there,
that means it's
picking up on it,
on your eyes.
First, let's get back--
Get-- Get you back.
There you go.
Got it.

[]

Do you just get really--
As you get used to it,
can you do it--
Can you--
Can you do it faster?

WOMAN:

Oh, gosh, yes.

STEVE:

Hi Michel, you rock.

[WOMAN LAUGHING]

It's the first time today,
man, I watched, uh,
some of my videos
from last couple days,
and I listened to myself
and I was--
Sound--
Probably sound--
Sound ill. Sound sick.
And that, uh--
It's tough, man.
I've been thinking about
fathers and sons
a lot since you've been born.
And...
at this point it looks like
we're not going to have
the normal father-son
relationship.
I can't go out and play catch
with you.
I can't throw you
a batting practice.
But, uh, I want to do
everything I can
to be a good father, uh,
to give you what a son needs
from his father.
And, uh,
I'm gonna be around, buddy.
It's not gonna be easy,
but it's gonna be awesome.
And I'm gonna be around until
you are able
to stand on your own,
as a man.

MAN:

Steve, how old are you?
Do you know what
your weight is right now?
So it's gonna be
24 inches wide,

it's gonna have
the casters up here.
The casters up here,
you don't have 'em on this chair
because it's a little more
stable base.

[]

[INDISTINCT DIALOG]

STEVE:

It's crazy, man.
I am to the point where
I barely go out of the house
by myself.
Michel goes
everywhere with me now.
She helps me shower.
She helps me
put on my clothes.
She helps me eat.
You have a mom
who's just incredible.
Incredible.
Remarkable, amazing.
And we're both
so lucky to have her.
I think any caretaker,
you're always kind of there
trying to make things
easier for him.
I just feel like it's--
It is-- It's what I do,
and it's-- It's our
relationship, it's what we do,
it's-- It's just kind of, like,
part of our life,
like this is--
This is what it is.
So I set up things for him
in the morning,
I set up things for him
at night,
help him walk,
help him brush his teeth,

help him--
Help feed him,
and it's--
It's just kind of like
a new part of life.
Just like it is
learning how to
take care of Rivers.
[BABY COOING]
Mm, mm-mm-mm.
[INDISTINCT]
[BABY COOING]
[BABY FUSSING]
Hey.
Hey, man, you're okay.

STEVE:

Kids are a lot of
frickin' work, man.
And, uh, we get up
every three hours
to feed you,
and when I say we
I mean Michel.
You like that?
And I can see it's
taking a toll on Michel.
She's getting tired.
And I'm gonna
think of ways to, uh--
To help her,
either having someone
stay over at night,
or something, we gotta
figure out something
because I'd like to somehow
ease that, uh, burden
a little bit from her.
So do you-- Are you--
Are you in that?
I mean, are you familiar
with any of it,
are you in the--
I mean, you look,

you're obviously
in good shape.
I mean, like, you are--
Are you, like, in the
therapy world, or--
No.
No?
He's a neighbor and,
big enough, like,
he's going to move me
where she might not be able to.
You know, he was my hero.
This is the guy that
I wanted to be growing up.
Turned out, you know,
he was dating Michel,
and Michel used to
baby-sit me as a kid.
When he was diagnosed
she asked me--
She gave me an ultimatum.
She said, "Blair,
you either quit your job,
or I'm gonna kick you
in your dick."
[GROANING]
Blair and I's life purpose was
to make sure Steve was happy.
There's times where
Steve would say,
what am I doing?
What's the point?
This is awful.
And we'd be like,
okay, like, what can we do?
Do a dance, build him up.
And it was--
We had a fucking
bad ass unit.
[]

MICHEL:

The journey into the lake,
part one.

...three, go.

[]

Damn!

Rivers, be a part of
the fuckin' team,
and eat your goddamn food.

Hey. Hey. Hey.

A-shoo, a-shoo.

Hey. Hey.

[BLOWING]

How long have I known you,
brother?

Hundreds of lives,
thousands of years

I feel like, in many ways,
I'm fulfilling my purpose.

I feel excited every day
to get up and-- And make
a difference and an impact
on people's life.

I feel like I've put together
a good team of people
to help take care of me.

Um, I've put together
a good team of people
to look for solutions.

People will say, "Oh, it's such
a sad, tragic story."

It is sad,
and so they're right,
but it's not all sad.

I think there is more
in my future than in my past.

I believe my future
is bigger than my past.

And so that's uplifting.

That's inspiring.

[BABBLING]

Bah!

[GIGGLING]

Bah!

[GIGGLING]

Lately, the coolest stuff
for me has been

you falling asleep
on my, uh, lap
while we drive around
in my chair.

MICHEL:

Which you need to name,
by the way.
You mean my
electric chair.
This isn't the
electric chair, though.

MICHEL:

EC.
You should call it gonorrhoea
because it's temporary.
[LAUGHING]

MICHEL:

Gonny?
Gonny.

MICHEL:

Gonorrhoea's temporary?

MICHEL:

Yeah. Penicillin
cures all that shit.
And doxycycline.
Somebody told me that.
[BABY FUSSING]
June 17, 2012.
Are you gonna shoot it?

MICHEL:

Look at the camera, Rivers.
Oh, Dad--
What?

MICHEL:

Oh, it's a video.
I didn't know that.
Why didn't you--

Why didn't you tell me that?

Then I won't be
sitting here like a s--
Stuffed, uh, pepper.

Hey, buddy.

So what are all
the numbers for, Steve?

[LAUGHING]

What am I missing?

Am I missing something?

MICHEL:

All right,
he's doing his, uh--
June 17, 2012.

Oh, I get it.

[LAUGHING]

All dads never think
that they're, uh,
annoying their kids
like they do,
so I have no idea
how I will annoy you.

[SIGHS]

I hope it's not the way
that my dad annoys me.
So your taste buds
still working pretty good?
You still taste stuff?
You act like you've been
eating [BLEEP].

You got all embarrassed.
Your sense of humor
still working?

[LAUGHING]

I'm sorry, Steve.

Dad.

What?

I just asked if your
taste buds were working.
Do you know anything about ALS?
Not a lot, but it
looks like it's not--
It's--

It doesn't affect
your taste buds.
I didn't know that.
Didn't know that.
I was not embarrassed.
I was laughing at you.
Oh, you were laughing at me.
'Cause I didn't know that.
Okay. All right.

MICHEL:

That was
one of the best just now.
What-- He's got--
My dad will go from zero
to over the line.
Then like you're like,
"Wait, what?"
So weird.

STEVE:

There's almost
nothing more personal than
a father-son relationship,
you know.
What I think is
so interesting is that, uh,
this is obviously--
This whole thing,
these video journals,
this film,
all this is about
a father and a son.
Um, my dad and I, I think,
believe a lot of
the same things,
but he's this wacky,
fundamental, literal, uh,
kind of single-minded man
who thinks that
I should believe
exactly what he believes
in order to be saved,
I guess.

I was diagnosed
with a terminal illness
and I know that
when you get scared
you're going to jump
to your camp
that I need to pray like you.
I need to believe all the same
things that you believe.
You promised me that you would
not question my faith.
Okay.

But every time you question
my faith it crushes me.
I-- I can understand that.
Because here's the thing
about faith,
you can't argue
with someone's faith.
That's true.

You can't debate
with someone's beliefs.
That's true.
Because there's no proof
either way.
Stop trying to understand
with your mind
the relationship
between my heart and God.
Okay.

My soul is saved.

Okay.

Don't be angry at me.

Please.

[SOBBING]

Stephen, you're my son.

[SOBBING]

You don't know
what it feels like inside
that-- That I might
lose you, man,
you don't know
what it feels like,
it's killing me.

[SOBBING]

Glad you came.

I love you, Stephen,
with everything inside of me.
I love you too, Dad.

[BABY CRYING]

Who the hell brings
their kid to this thing?
All right, ready?

[LIP BUZZING]

[COOING]

I'm out of breath.
I think part of what we
do every day is search for
something that's....
permanent stabilization,
and,
you know,
maybe that's not out there,
but I'm hopeful. I'm hopeful.
All right, bud.
You'll be great.
Prick you here, okay?

All right.

[MACHINE HUMMING]

There's been cases where
stem cell has worked.
Some ALS patients
will have the procedure,
and they will not progress
any further.

MICHEL:

We spent lots of time
in the hospital.
Like, just sitting there,
so I needed to do something
so I just started drawing.
When I was drawing,
I could completely ignore
any doctors that came in,
or anybody who came in
that I didn't want
to talk to.

I just completely
can zone out.
He wants us to call
an ambulance.
Ask him if we should.
Ask him if we should.

BLAIR:

After that surgery,
there was definitely
an adverse effect,
and he was in such
a large amount of pain,
he was convinced that
he was gonna die.
I love you.
You love me?
I love you too,
are you scared?
You are?
Earlier this week
I had stem cell therapy.
And, uh...
so far, not so good.

MICHEL:

All right,
with steady pressure
gently insert enema tip
into rectum
with a slight
side to side movement
with tip
pointing toward navel.
Michel, look,
you have to be able to do this.
Okay.
Don't get me down there
and make me wait
for fucking 10 minutes, okay?
Okay?
Yeah.
Okay.
Is this your butt?

BLAIR:

[LAUGHING]

MICHEL:

BLAIR:

It's all in.
Besides the stuff
that's in his--
I don't think anything went in.
You didn't feel it?
Nothing.
God-fuckin'-damn it!
Who knows about enemas?
Judy Robert,
thank you for coming.
We have some--
We have some
questions for you.
Judy, do you know
what you're about to
get yourself into?
I have a whole bottle
of lube.
What kind of lube
did you bring?
Is it scented?
I have--
Actually, I think it is.
It is.
What scent did you get?
Um, baby powder fresh.
Baby powder fresh.
I love that smell.
It's a truly
beautiful smell.
So, what are you expecting
out of Steve today?
Um, a lot of shit.
[LAUGHING]
I hope to get a lot of shit out.
All right.
I'm gonna know you

in a whole new way.
So do you feel it?
I mean, does it feel--
We record--
Recorded Steve earlier.
"I feel like
there's a football
lodged in my ass."
Okay, so, yeah,
there's probably like this.
You all right?
[STEVE GROANS]
Judy,
What?
am I the hottest guy
you've ever ass fingered?
[LAUGHING]
[STEVE GROANING]

JUDY:

That's it. That's it.
Rivers.
I'm having a bad day.
I'm an asshole to people,
and I don't care.
I can't talk.
I think the--
The last of my
talking days are here.
The drugs I take don't work.
I have no faith that I can heal.
I have no hope. None.
No hope whatever.
I want to punch
something, but I can't.
The only thing I can do
is scream.
[SCREAMING]

DREW BREES:

"On Monday,
September 25, 2006,
"Steve Gleason
was responsible for

"one of the most
dramatic moments
"in New Orleans Saints
history.
"He blocked a punt
in the first quarter
"of the team's return
to the Superdome
"following hurricane Katrina.
"That blocked punt,
that season,
"symbolized the rebirth of
the city of New Orleans."
Amen.

[APPLAUSE]

Yesterday, about five minutes
after I got home
I pooped all over myself
and my wheelchair.
And I think it's crazy
that I can go from
people saying,
"You're my hero,"
to having to be helped
onto a toilet
with my pants full of shit.
It's an incredible example
of polarities,
and dichotomies,
and juxtapositions
that is my life.
Happy birthday,
dear Rivers
Happy birthday to you
[CHEERING, APPLAUSE]
[INDISTINCT CHATTER]
[]

WOMAN:

When you blow out,
you gotta blow out
hard and fast,
'cause it's measuring
how much you get out

in one second, okay?
A normal breathe in.
Suck in.
Now blow, push!
Push. Push, push, push,
push, push push,
push, push, push, push,
suck in big.
That's terrible.
Uh-oh, we're not
accepting that one.
It's supposed to
look like that.
When did you get this?
You didn't have this
last time when I saw you.
A few weeks ago.
That's so cool.
This setup I have
costs \$6,000,
but others cost 20k.
[MOANS]
[BABBLING]
[MOANS]
Alligator.
Mom.
Alligator.
I love him.
Ah. Daddy.
[LAUGHING]
Say it again, bud.
Daddy.
Daddy.
Daddy.
Daddy.
[BABBLING]
I love him.
[BABBLING]
I love him.
[BABBLING]
Rivers, I want to
talk about obstacles
in adversity.
No matter what,

how wealthy you are,
how poor you are,
we all face adversity.
I do not want you to fail,
but I want you to
put yourself out there,
and available for
potential rejection.
In ways, I think,
that's how we succeed
because that's how we grow,
and that's how we
gain perspective.
When I'm wiser
And growing taller
I will see your way
When I've come to the
Places I'm goin'
I will know your ways
Ooh
Ooh, ooh, ooh
Ooh, ooh
Ooh, ooh, ooh
I can feel it hurt now
I can turn this pain plain
Try and see it clear
But I don't know
why it's here
No!
Whoa.
You can keep
the sound down
As long as you want now
Dude, yeah
You can push it on another
Damn, that man's
your brother
Oh-oh.
When I'm wiser
And growing taller
I will see your eyes
When I'm wiser
[LAUGHING]
And growing taller

I will see your eyes
When I've come to
the places I've been
I will know

MICHEL:

Yay!

[RIVERS SHOUTING]

[VOICES ON TV]

I wasn't sleeping
at night because I was
caretaking for Steve.

[VOICES ON TV CONTINUE]

And then, uh, the addition
of Rivers getting
a little bit more needy.

It was hard doing that
plus taking care of a kid.

[TV continues]

At some point
put Rivers on my lap.

At some point
put Rivers on my lap.

Rivers, look at me,
You do not hit your mom.
You cannot hit your mommy.
You're going to go
to time out.

[CRYING]

All right, buddy.
Now you know you cannot
hit your mommy.

[CRYING]

You understand why
you were in there?
Because you hit me
three times.

You cannot do that, okay?

All right, bud?

People started saying, like,
"Michel, you need help,
you need help,
you need more help,"
and it's kind of like,

well, this has turned
into my purpose,
and I don't want to seem weak,
and, like, I see
other people doing it.
Can I get a pillow?
Come on now.
Honestly, I think the enormity
of what she's going through now
and dealing
with this situation
just takes all of her energy.
I still think
she's trying her best
to do as much
as she can for people
and especially for Rivers
and Steve and her family
and struggling just to deal
with the situation.
It's easier, almost,
to, like, make a difference
with the world
with this disease.
It's, uh, some face time
on TV or some speeches
or some Tweets,
versus, like, the reality
of the hardness it is
to maintain relationships
when you can't move
or help or talk,
and so we're just kind of
traveling like this,
like we're not separating,
but we're separated in what
we wanted to do with life.

WOMAN:

Tonight the federal
government is saying no
to some devices that give
people with disabilities
a voice literally.

MAN:

Recent changes
to Medicare and Medicaid
have limited
ALS patients access
to speech generation devices.
Team Gleason became
one of the only entities
that was giving
these speech devices,
so the people
that couldn't afford it
through Medicare anymore
still wanted to communicate,
and we wanted them to be
able to communicate,
so we just started fulfilling
all of our requests,
which meant it was 2
and 3 and 400,000 a month.
We were able to fill
every request
that people asked of us.
So much so that it's depleted
our money that we had,
so we're now actually going out
and beating on doors
and asking people
for money again.

WOMAN:

Former Saints team captain
Steve Gleason
and his foundation
organized a Gleason Gras,
a music celebration
at Champion Square
to raise money
and awareness about ALS.
When I say "Gleason,"
you say "Gras."
Gleason!

CROWD:

Gleason!

Gras!

MAN:

Thousands gathered
to celebrate
the inspiring effort
of one man.

You've changed my life.

You're so great.

We went up to Washington
and met with the Secretary
of the Department of Health
and Human Services
and pled our case.

We hope to pass this law,
and once again Medicare
will pay for these devices.

[RIVERS FUSSING]

No.

Yes.

One bite of this,
and I'll give you chips.
We had no idea Steve was
just going to get bigger
and bigger and bigger.

I think with Team Gleason,
he's putting too much
into Team Gleason
and not doing enough
of his video journals
and stuff for Rivers.

I think

it's a balancing act.

We all have to balance things.

It's kind of his balance.

And it's a huge--

It's super-hard.

[SIGHS]

VOICE SIMULATOR:

This is the most
significant achievement

for Team Gleason to date.

[CHEERING]

What's going on here, Rivers?

See all the cameras?

You like it in here?

VOICE SIMULATOR:

Hey, Vavoom, what you doing?

What you doing?

Steve has wanted

to be a hero,

and it's amazing

that he has gotten--

And he is legitimately a hero--

Like, of a town

for blocking a punt,

and now, like, the face of ALS.

But people come up to me

and be like,

"Congratulations."

And you're like, "For what?"

Like, "What are you talk--"

Because, like, "What?"

What do you mean?"

It's just such a--

This whole thing

is a huge mind fuck.

STEVE:

It's important to me

that we do Rivers sandwich

and nose kiss every night,

Michel.

That's the only physical time

I get with him all day.

Okay.

You tried

to skip it tonight.

Okay.

And you took-- Okay.

Thanks.

Thanks.

You're welcome.

I didn't mean it stupid.

I just didn't think about it.
Are you okay, Mick?
Great.
Yeah.
Shit.
Are you okay?
Yep.
I feel like you have no
compassion towards me.
Everything is rushed.
You always have
somewhere else to be.
You finish my sentences.
You rush any care
that you give me.
I don't understand
what I did to deserve it.
Please tell me
how I can improve.
You walked by me
ten times tonight
while Rivers
was on my lap.
I tried to get
your attention.
You didn't
even look at me.
Sorry.
I don't think it's anything
you can improve.
I think
it's how I can improve.
Do you feel angry
when you are with me?
Um... No.
I feel more angry with myself,
for how I feel in general.
What can I do to be
more important to you?
I don't know.
If you want to talk--
You don't have to,
but if you want to,
I will listen.

Thank you, buddy.

[PLAYING GUITAR]

MICHEL:

That's my favorite song.

MAN:

Your favorite song

is "Come Back"?

[CHATTER]

I must say I have done some
amazing stuff in my life,
but this experience was
right at the top of the list.

I just interviewed Pearl Jam
on their latest album.

The music

you guys have created
has plastered the wall
of my adolescent
and adult life.

I want to thank you
for providing
the significant portion
of the soundtrack
for my life.

I have my son Rivers.

I am assembling a video
journal library for him
in case the experts are
right about my timed life.

You did not know your dad.

What are a couple of things
you wish you knew about him?

Yeah, see if I can
get through this. Um...

That's a great question
and coming from you.

Um, I couldn't
appreciate it more.

Um...

Of course I think
just deep down I just would--
Would have wanted to know

just, you know,
if he loved me
and how much, you know.
I get the idea that he did,
you know.
But, uh, the other nice thing
would have been
just having, um,
someone of my own blood
give me some insight of--
And, you know,
what it would be like to...
grow up and, you know,
be a man, a good man.
I wish he was around now,
and I like to think
he'd be proud of me.
Thanks, man.
I-- I knew this was
going to come in
handy for something,
but I didn't know what.
Steve Gleason sitting in
for Barbara Walters this week.
Rivers, you are
an awesome boy or man,
depending on what times
in your life
you happen to watch this.
But the world
can grind on you.
Do not become obsessive
to the point
where you are unhappy.
Let your best stand
for what it is.
If it's not sufficient,
that's okay.
You did your best. Move on.
We're a grassroot,
pretty much, you know,
pro bono kind of things,
volunteers,
that has done in two years

some incredible things.
To live with ALS
is hard enough as it is,
but I think to live in the way
that Steve is living with it,
you know, to be so
out front and public,
uh, there's a lot of sacrifice
comes with that,
and I think it's a sacrifice,
you know, on your family
and to have your priorities
in the right place.
You know, we have to reflect
on where we need to be.
I think it's going
to be up to Steve,
knowing that all these
people want to partner up
with, you know, where he wants
to go, in which direction.
I realize that I have pushed us
to the point we are right now,
but I think I need
to get more into balance.
I am frustrated
because I have only written
two or three journals
in the past few months.
I am tired. Michel is tired.
I think we, Michel and I,
need to pull back quite a lot.
It was like music to our ears
because it's like
finally Steve is going
to take a step back
and just focus
on what really matters,
and that's his health,
his relationship with his wife,
and his son Rivers.
I have never wanted
to be a saint.
I've never been a saint

before Steve.

I'm never going to be a saint.

I don't want to be,

like, a devil

or a dick face, but I don't

want to be a saint, either.

I just want

to be a real person.

One, two, three, go.

[GRUNTS]

[CHATTER]

This is brutal.

Just when we spoke to that

doctor a couple of weeks ago,

he's like-- Essentially, you

can live as long as you want,

but there's a reason

people choose not to

because life is so sucky

that it seems

like that they choose,

like, "Hey, this is

a better option," you know?

Um, so I think that's

what I'm really scared of

is, like, I have a little bit

of control over when I die,

maybe, but may--

That might be false,

like maybe not.

Maybe there's--

I don't know

how it happens, you know,

when people with ALS get

to the death point, you know.

Give him a big one.

Give a big--

Is this a salami sandwich?

[PLAY MUNCHING]

I think it's

a chicken sandwich.

[PLAY MUNCHING]

[COOING]

I know when we first met when

you were able to communicate
very clearly at that time,
early in the process,
you were very clear
that as things moved forward
you were gonna utilize
any available technology
to stay in the game.
Comfortably, with the best
quality of life
that you could have.
That I know has been your goal,
but I wanted to revisit that
with you.
I have had the opportunity
to contemplate my own death
quite thoroughly
the past few years.
I say it's an opportunity
because I think understanding
one's mortality
can help open a person
to lead a more meaningful life.
I fight to stay alive
for my son,
for my wife, my friends
and family.
I am not giving up.
One of the things that I
always admired about him,
it felt that their relationship
will continue for a long time,
is that they could tell each
other everything and anything.
Honest as could be, truthful,
and that has been
lost in the process.
Oh, my God,
I can't believe
I just hit
the wall
from two nights ago
just now.
Why don't you--?

Why don't you go--?
Just lay down.
We'll be quiet.
I'm working on
a masterpiece.

STEVE:

And you are planning
a bronchial sweep.
Yes. I'm going to look down
with a flexible scope
and suck out all that stuff
out of your lungs
so that hopefully that sticky
sensation that you're feeling
will be gone.
Great.
Well, I am anxious
but feel good with you.
Thank you.
I appreciate it, okay?
We're going to take good
care of you, I promise.
All right. I'm going
to head on down
and make sure everything's
set to go, okay, buddy?
I'll see you
in a little bit, okay?
I promise you we'll take
great care of him.
Sorry you have to deal
with this.
It's the White Flags,
Gleason. Go get 'em.
If for some reason
something happens
and you can't understand
him, come get us, okay?
We're staying
right here, baby.
I'll keep you
guys posted.
And we'll take good,

good care of him.
It's a hard time because
it's all of a sudden
like I don't want to think
about how sad it is.
I don't want to think about
what we're missing out on.
I don't want
to think about myself
because it's depressing.
I don't want to think
of these things.
It's finished.
What's that called?
That's beautiful.
It's called "Commotion
of Colors In Motion"?
Yes.
You have to give
your--
Ooh. Ooh. Okay.
And that's called
"emotoling"--
emotion doodling.
Emotoling.
Emotoling?
Emotoling.
Emotional doodling.
Emotionally doodling.
Okay.
I like that.
Oh.
The dilemma is, ahem,
obviously we want him to live,
and the longer he lives,
the harder it'll get.
But-- And-- And for her,
it's realizing that
the longer he lives,
the longer she has
to deal with this,
so it's just-- It's tough.

RIVERS:

What's that?
That's a-- That's
a trach and a vent.
Because guess--
Remember what Dad has--
Daddoos has? ALS.
Remember?
Happy birthday, dear Rivers
Happy birthday to you
Blow 'em out.
[APPLAUSE]

MICHEL:

You have to
blow harder, Rivers.
[CHATTER]
[CHEERING]
Last two.
All right,
Rivers.
It's not a yay yet.
He's a chicken.
[LAUGHTER, CHATTER]
I want you to
finish strong.
All right.
[CHEERING]
[CHATTER]

RIVERS:

Rivers,
did you make any
new friends today?
No. I didn't...
Did you play
with Goren today, bro?
No!
He had fever.
[MICHEL CHUCKLING]
Can you count
to October 19th?
One, two,
One, two,
three, four--

Three.

Four, five, six, seven.

Oh, one, two, three, four,
five, six, seven.

My second reading
of "The Little Pea."

I'm excited for the day
when you are
teaching me things.

As a father, my goal
is for you to be--

To-- To teach you
to think for yourself,
and there's a downfall
to that

that eventually you'll
be thinking things
that are different
than things that I think.

In the weirdest way,
that's the goal,

but then you don't think
the things that I think,
and we have disagreements
or debates or, um,
differing opinions.

So my point is that I'm
saying now to you
that I am excited
for that day,
even if, when that day comes,
I'm frustrated.

Okay, tough guy,
so what kind of questions
are we going after here?

Four years ago, we had
a similar conversation.

What has been the most
challenging moment for you
since my diagnosis?

Uh, having to deal
with the day that you die.

Well, you asked me.

And I ask myself why--

You know, why did it have
to happen to Stephen?
But a simple answer for me
is, I mean,
it's the way
you played, Stephen.
That's why those coaches
loved you--
Because you were just
relentless.
We've had a couple
on-camera moments
talking about
our spiritual beliefs.
Do you feel at peace
about that?
I was talking to you
about some things,
and you were starting
to lose your voice,
and you says, "Dad,
don't worry about my soul.
My soul is saved."
And I don't think you could
speak that out of your heart
if you didn't really believe
that your soul was saved,
Stephen.
So I believe
your soul is saved.
If you could go back,
what would change about your
philosophy of fatherhood?
Oh, man. Uh,
probably being gentler.
Uh, I'm sure I could
have worked a little
smarter at things.
I think you did well.
Well, thank you.
I think you've taught Rivers
more about love and gentleness
and kindness at an early age
than I even knew about.

But it's pretty cool
to watch how you sing to him
on that, uh, computer
and get him in your legs
and he rolls around with you
and you say
bedtime stories to him,
and it's pretty awesome,
Stephen.

Rivers feels all of that
in his heart.

Some day he'll walk through
that Saints locker room,
and he'll see your picture
on that picture Hall of Fame
for the Saints,
and, you know,
he'll walk to the stadium
and see his dad's statue,
and, you know.

I just hope he doesn't feel
like he has to try
to accomplish as much as you.
All I know
is that you wouldn't put
that kind of pressure
on him.

RIVERS:

Go! One, two, three.

A year from now

We'll all be gone

Hold this. Come on.

All right, Dad,

let's do it.

And they're

going to bed...

[LAUGHTER]

Go! Say "Go, Daddoos, go."

Go, Daddoo, go!

My friends will be gone

I think his main purpose

now is,

you know,

being a dad for Rivers,
the best dad that he can be.
Nothing is as it has been
And I miss your face
like hell
I've lost a little bit
of the happiness and light
that was a big part
of my personality,
and I'm trying to find a place
where I can get that back
because I think it's important
because it's a big part of me.
I think of having a show
at some point.
That's way out
of my comfort zone,
and I'm, uh, I'm not
there quite yet.
Yeah. Being an artist
is just, like,
kind of complicated.
Luckily, I'm not an artist.
I think I'm better
than last year,
and so next year
might be even better.
But this is a motherfucker.
That's that.
I'm still pretty funny.
[VOCALIZING]
Go!
Whee!
Whoo!

WOMAN:

The Steve Gleason Act is
now the law of the land.
Word came down tonight
that President Obama
signed the bill
into law today.
The Steve Gleason Act
will give immediate relief

for patients who have
been denied access
to speech generating devices,
and it will ensure that
eye tracking technologies
are covered under
Medicare and Medicaid
for ALS patients.
Rivers and roads
Rivers and roads
We've gone from a family
member who has ALS
to now almost a
hero-slash-poster person
who started a movement,
and the movement
is its own entity now,
and it's strong, so it's
taken its own life,
and I think that's probably
as critical as anything.
Rivers and roads...

STEVE:

Fundraisers
and all that stuff--
Really none of that
is as important
as this right here.
That's all that matters
is me passing myself to you.
Here's a memory from
my high school years.
How to build a campfire.
Dating.
Obstacles.
Trying to give you
everything that I can.
Even if I'm not
present physically,
you'll have this,
and I feel so much better
when I just sit down
and share myself with you.

Rivers till I reach you
Because that's what dads do.
They pass stuff on,
the best of themselves,
to their kids.

Rivers and roads,
rivers and roads
Rivers till I reach you
Rivers and roads
Out.

Rivers till I reach you
All right.
Test, test, test.
Test.

Rolling.
It's right in the middle
of the state--
That's your mom, dude.
What the hell.

That was awesome.
She's a piece of work,
I tell you what.
When I feel something
strong enough,
it takes over my head,
and I had to just say it.
I had to say "Steve, I had
a dream that I liked you,
and I think--

I think that I like you."
...for hundreds of miles
Boo!

This is me giving you a hug.
Just...
Making these videos is my hug.

...down on his knees
Oh, life came crashing
unofficially down...

Unfortunately,
this is real life.

It's not a movie, so,
I'm trying to make it as
hunky dory as possible.
But I think sometimes

real life gets in the way.

[VOCALIZING]

[SCREAMING]

My thoughts for you

and tattoos'

remembrance is this.

Do not get it of

your girlfriend's name.

Or your wife,

for that matter.

Hey.

Or your wife.

But your mom's,

you can get one

of your mom's if you want to.

And I do believe

that in five years

I'll look back on this video

and say "Wow,

"that was the beginning

of, you know, this journey

that has turned out so much

for the better in my life."

And he still

gives his love

He just gives it away

The love he receives

Is the love that is saved

I just want to say

I feel like I'm

exploding on the inside.

I love you so much, man,

and, um,

that's a great thing,

and I hope, uh,

you love me

as much as I love you,

but it's impossible.

I think even better is I hope

you love your children

as much as I love you.